ASTP | Health IT Advisory Committee

Health Information Technology Advisory Committee

Health Equity by Design (HEBD) Task Force 2024 Virtual Meeting

Transcript | December 11, 2024, 2 – 3:30 PM ET

Attendance

Members

Hannah Galvin, Cambridge Health Alliance, co-chair
Shila Blend, North Dakota Health Information Network
Medell Briggs-Malonson, UCLA Health
Kristie Clarke, Centers for Disease Control and Prevention (CDC)
Sooner Davenport, Southern Plains Tribal Health Board
Derek De Young, Epic
Sarah DeSilvey, Gravity Project
Steven (Ike) Eichner, Texas Department of State Health Services
Susan M. Jenkins, HHS Assistant Secretary for Planning and Evaluation (ASPE)
Kikelomo Oshunkentan, Pegasystems
Rochelle Prosser, Orchid Healthcare Solutions
Belinda Seto, National Institutes of Health (NIH)
Christopher St. Clair, U.S. Food and Drug Administration (FDA)
Janée Tyus, IMPaCTCare Inc, University of Michigan-Flint and Michigan Health Information Network (MiHIN)

Members Not in Attendance

Hung S. Luu, Children's Health, co-chair
Cynthia Gonzalez, RAND Corporation
Meagan Khau, Centers for Medicare & Medicaid Services (CMS)
Naresh Sundar Rajan, CyncHealth
Janice Tufte, Hassanah Consulting

ASTP Staff

Seth Pazinski, Designated Federal Officer
Whitney Weber, Support Team
Maggie Zeng, Support Team
Mark Savage, Task Force Program Lead

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

Seth Pazinski
Hello and welcome, everybody, to our Health IT Advisory Committee's Health Equity by Design Task Force meeting. I am Seth Pazinski with the United States Department of Health and Human Services (HHS) Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP), and I will be serving as your Designated Federal Officer for today's call. As a reminder, this meeting is open to the public, and we encourage public feedback throughout the meeting. Comments can be made via the Zoom chat feature, and there is also time scheduled at the end of our agenda for public comments. I am going to begin with a rollcall, so, when I call your name, please indicate that you are present. I am going to start with our co-chairs. Hannah Galvin?

Hannah Galvin
I am here. Good afternoon.

Seth Pazinski
Thank you. Hung Luu? Shila Blend?

Shila Blend
Present.

Seth Pazinski
Medell Briggs-Malonson?

Medell Briggs-Malonson
Good afternoon.

Seth Pazinski
Thank you, Medell. Kristie Clarke? Sooner Davenport?

Sooner Davenport
Hello, present.

Seth Pazinski
Thank you. Derek De Young? Sarah DeSilvey? Steve Eichner?

Steven Eichner
Good afternoon.

Seth Pazinski
Good afternoon. Cynthia Gonzalez? Susan Jenkins?

Susan Jenkins
Here, present.

Seth Pazinski
Thank you. I did get a message that, unfortunately, Meagan Khau will not be able to join us today. Kikelomo Oshunkentan?

Kikelomo Oshunkentan
Good afternoon.

Seth Pazinski
Good afternoon. Rochelle Prosser?

Rochelle Prosser
Present, good afternoon.

Seth Pazinski
Thank you. Belinda Seto?

Belinda Seto
Good afternoon, I am here. Thank you.

Seth Pazinski
Good afternoon. Christopher St. Clair?

Christopher St. Clair
I am here.

Seth Pazinski
Thank you. I did get a message that Naresh Sundar Rajan and Janice Tufte will not be able to join us today. Janée Tyus? Okay, thank you. Are there any members I missed or who just joined us that would like to indicate that they are present?

Derek De Young
Derek is here, from Epic.

Seth Pazinski
Thank you, Derek.

Derek De Young
Sorry I am late.

Seth Pazinski
No problem. Well, thank you, and I am going to turn it over to Hannah Galvin for opening remarks.

Opening Remarks (00:02:24)

Hannah Galvin
Thanks, Seth. Welcome, everyone. I want to start by extending my congratulations to ASTP for the Health Data, Technology, and Interoperability: Patient Engagement, Information Sharing, and Public Health Interoperability (HTI-2) final reg that dropped today. I know that was ton of work, so, congratulations for getting that through the door. Thanks to everybody for joining today and for your continued commitment to this critical work as we move this forward. I think we have really made some significant progress, and we hope to finalize the framework between today and next time and really get our recommendations off the ground and running. Thank you so much for all the expertise that you bring to the table and for your continued dedication to this work.

Seth Pazinski
For our agenda for today, we are going to have a brief presentation by our co-chairs to go over the task force framework for recommendations and discussion, and then, the bulk of our time today will be spent in a task force discussion providing feedback on that framework and the different pieces within it, as well as identifying potential areas where we might want to invite some Subject Matter Experts (SMEs) to join upcoming calls, and then we will have our public comment and close with next steps. Go to the next slide. This is just a reminder of our charge. Go to the next slide. Hannah, I guess I will turn it over to you if you want to go over some of the clarifying points on the charge.

Hannah Galvin
Yes, that sounds good, Seth. We went over these on the last call, but just to go over them again, for Point No. 1, which is making recommendations to health and human services organizations, the focus there is really on, first of all, healthcare delivery organizations as opposed to, say, federal agencies, so our focus is really on healthcare delivery organizations, and our focus is on data foundation and how we can use health equity by design approaches to capture, use, harmonize, and exchange health data, as well as what types of data should be leveraged by, again, health and human services organizations, but really, healthcare delivery organizations to better promote health equity. What should we capture? Should we be capturing social drivers data, sexual orientation, gender identity SOGI data, or Zone Improvement Plan (ZIP) code, or not, and what are some of the pitfalls there? We actually had a pretty robust internal discussion about that yesterday, and we highlighted the potential for some small-scale implementations that may have been done, and possibilities for expansion there. That is Point 1, and we wanted to get a focus down in terms of what ASTP leadership's vision was because what is written in the charge is so broad, so that offers some additional focus.

Point 2 is really focused on what may not exist today, where we need ASTP's help for recommendations going forward, so it could be focused on what ASTP can do today, but also going forward into the future related to policy, standards, certification, and also in its coordination going forward, so that can be related to both data as well as wider-scale technology strategy, so those were the clarifying points trying to help us focus a little bit. Next slide, please.

So, these were some example components as we start to think about our document and what we may want to have in that blueprint, where we want to have our objectives, understand our audience, whether we have some limitations, and outline those. We may want to have some terminology discussion, and we may want to explain our framework and how the information is organized, and just think about how we want to organize this document, which we might talk about more with this group. But today, we are going to focus on our framework, so, next slide, please. As we were talking about our framework, this was one of our slides that we went through, but I think we have moved past this a little bit, so we can move forward to the next slide, please. So, some of the objectives that we have talked about today… Seth, do you want to take this slide, or do you want me to keep talking and discuss it? Can I keep talking?

Seth Pazinski
Yes, you can keep going.

Task Force Framework for Recommendations and Discussion (00:07:47)

Hannah Galvin
Sounds good. So, today, we are going to talk about the draft framework that we have come up with based on all of your feedback, on the challenges that we talked about, and the themes and subthemes that we pulled together from all the excellent feedback and expertise that this group provided in the edits, homework, and all the feedback you have given us. We will talk a little bit about how we came to this and how we aligned with data justice

principles, and we want to get your feedback on that. So, the homework for the next week is to take this draft framework and make any edits that you have. If there is anything that we may have left out, we would like feedback on this draft framework. We are going to talk about some examples for how this framework translates into recommendations. These are not necessarily our recommendations. We are just going to give a couple of examples so that we can envision how this may translate into recommendations going forward.

And then, going forward, we want to identify any themes or subthemes that you may want to add or remove, change the verbiage, and wordsmith in any way, as well as any subject matter experts that we might want to have come speak to recommendations where we may not have the expertise on the task force if we want to bring somebody else in. The caveat there, which we will talk about more at the end, is that we want to do that relatively quickly. We really want to do that in the six weeks in January to mid-February because we are on a pretty tight timeline here.

We need to present our recommendations to the broader HITAC in early April. We said that this has to be finalized by the end of April. Seth or Whitney, tell me exactly when, but I think we are scheduled in early April to present this to the broader HITAC, which really means that we have to have our draft final recommendations done by the end of March or early April so that we can present them to the broader HITAC, they can give us any feedback, and then we can finalize the recommendations by the end of April, and they can vote on them. So, we are working in a pretty tight timeframe here, so we want to get any subject matter expertise that we may need by mid-February at the very latest so that we can then really move forward. All right, next slide.

All right, let's jump right into the framework. So, we took the themes and subthemes that you guys gave us and discussed at previous meetings and also shared with us offline as well, and I want to thank Medell for sharing some of her expertise and presentation that she has, specifically a framework on the principles of data justice, and we adapted that framework to this and applied the themes and subthemes into that framework. Part of the reason that we did that was because when we saw how the themes and subthemes sorted out, they really sorted themselves into that framework, so we just aligned it. They naturally aligned into that framework, and we thought there was an existing framing for the principles of data justice, so they fit very nicely into that, and that is how we wanted to align them into an existing research-based model where we felt they fit nicely. So, this is how we represented them, and I hope that we captured the elements of the discussions that we have had over the past number of weeks. I am going to come back to this screen in a second.

Can we just jump down past the examples to the graphic? So, this is how this would then come together, and we will go over some examples in a second. The themes and subthemes will be on one side, and the guiding principles were actually adapted from some guiding principles that Gravity Project uses, so we should give them that attribution there as well, and thanks to Sarah for pointing that out. We want to give appropriate attribution to our various stakeholders who have lent their frameworks to this discussion. We will want to make recommendations on each of the themes and subthemes that are appropriate to the two pieces of the charge, all informed by our guiding principles, and so, that is how we envision this.

So, we will come back to the themes, but if we go back to the first recommendation example, for a theme around transparency with a couple of subthemes, like one around data standardization and collection across different types of data and another around improving data collection and quality, here is an example of a possible recommendation. We as a task force could recognize the importance of collecting race, ethnicity, and language (REL) data and SOGI data to advance health equity that goes to one of the asks of us in our interpretation of the charge, which is that we identify types of data that need to be collected in order to advance health equity. Again, this is just an example, and we need to decide what we recommend, but we may recommend that health and human services agencies, to Point 1 of the charge, use CDC and United States Office of Management and Budget

(OMB) standards to measure this data, and, No. 2, to the second part of the charge, the recommendation to ASTP is to work in its coordinating role to align state and federal agencies with the CDC and OMB standards.

I say that from personal experience. The Commonwealth of Massachusetts requires collection of this data, and it is not currently aligned with the OMB or CDC standards, which makes things very challenging, which is one of the reasons I gave this example. I wanted to give a view into how we may translate the themes into recommendations. I think this is just an example of one of our recommendations. If we could skip to the next slide, another example, which those of you who know me will know why I give it, is around privacy. If something needs data segmentation and consent and aligns with our guiding principles of promoting trust and ensuring personal control, if the task force recognizes that some individuals have specific considerations around their REL and SOGI data or other types of data, to Point 1 of the charge, we could recommend that health and human services organizations allow patients to indicate if they prefer that their data is shared or not in specific circumstances. That is specifically related to data and how data is exchanged.

To Point 2, a recommendation for ASTP is that it funds ongoing standards development related to data segmentation and consent. This attends to each point of the charge. Does that make sense in terms of those recommendations? Why don't we go back up to the slide where we have the framework and just spend some time with discussion around the framework itself? Are there any questions or thoughts about the examples or how this is put together? I will just open it up for discussion. Are there any themes or subthemes where people have questions or feedback on the wording? We will also have the whole week to collect feedback, but I am happy to open this up for discussion, to start.

Task Force Discussion (00:16:42)

Medell Briggs-Malonson

Hannah, I believe Ike has his hand up.

Hannah Galvin

Sorry, Ike. I cannot see everybody on my screen. Please go ahead.

Steven Eichner

I am not sure if it fits in the framework or is a foundational component that might be a background element, but thinking about foundational elements as a toolset to use, thinking about technology and data standards as a core footprint that we are building this framework on top of, as we talk about the general concepts of race and ethnicity data as resources, for example, as the code sets that are supported in the United States Core Data for Interoperability (USCDI), not as a framework element, but as a foundational piece upon which to build all the framework and components as resources to inform or support this other work.

Hannah Galvin

Ike, do you think that might go under the important data elements for health equity under transparency?

Steven Eichner

No, I think it comes before it. I am not talking about how to use it. Looking at the transparency piece might be how to apply the data standards. I am thinking of it more as a fundamental anchor point to create the foundation upon which all these other elements are built: In the context of the healthcare provider, using or developing healthcare technology or health IT to do these things, looking at the data standard as a resource upon which to build the rest of the activities. In other words, looking at the data collection, talking about transparency of the data collection and use, but looking at the fundamentals of where you are putting the data is kind of a fundamental element, and I

think providing some context about what existing supports already exist to operationalize all the concepts that are talked about in the framework makes sense.

Hannah Galvin
Got it. I just want to make sure I understand, Ike. Would that be separate from the data standardization and collection, or even just the standardization? Would you have that as a separate theme, and not fitting in any of these themes?

Steven Eichner
I think so. As I said, I do not even think it is necessarily a theme. I think it is a foundational, fundamental, and environmental resource descriptor. If you are talking about, say, the OMB/CDC guidelines, that is not so much a transparency element as a foundation upon which the rest of the stuff can be built or modified, right? So, we are looking at the exchange of data and looking at Health Level 7 (HL7) standards for USCDI that form a foundation for these other activities. Now, that does not mean those foundational elements might not need to get changed or updated, but they are part of the environment upon which things can be built. We do not have to start inclusive representation or transparency from nothing. We have some tools that are already in place that we can begin to leverage, and I think there is value in communicating that there are some tools upon which we can build. We are not starting from nothing.

Hannah Galvin
Yes. I think that is great to call out.

Steven Eichner
The other piece not a foundational element, but we should look at the term “standards-based” or “evidence-based” practices. That is a buzzword that is relevant for a lot of components, and I am not sure if it is a framework item or a consideration, asking how we fit equity by design into standards- and evidence-based practices, but again, I think that is a highly popular term that probably needs to be included here, and we may be willing to modify evidence-based practices or develop new evidence-based practices based on additional evidence around race and ethnicity. But again, thinking of the terminology becomes really relevant and really important because that is what a lot of practitioners and policymakers are used to seeing as a term. Let’s adopt the terminology and use it and our familiarity with it to our advantage in speaking to our audience.

Hannah Galvin
Those are great points. We will be very interested to understand, and I would love to hear more. This is just the framing, and we will want to flesh it out more in our actual recommendations, but we want to know what you and others think in terms of where that might fit specifically in the framing. You might propose an additional theme, subtheme, or modification of the verbiage of a subtheme to include some of that language, “evidence-based practices,” and I can see that going under harm and bias prevention, for instance. Incorporation of health equity by design principles into evidence-based practices might be a subtheme there.

Steven Eichner
I was not trying to park the term, but just had a spontaneous thought that this is a term that is relevant. It probably needs to fit in somewhere.

Hannah Galvin
Yes, I think that is a great point. Anyone else? For some reason, I did not see your hand raised, so I just want to make sure I am seeing people’s hands raised. There we go. Medell, I think yours is first.

Medell Briggs-Malonson

Yes, you have a couple of people with your hands raised. I believe Belinda is up next.

Hannah Galvin
Oh, Belinda.

Medell Briggs-Malonson
First, it is fantastic that we are putting this into a framework, so I think we can all start walking through this and trying to see what subthemes are there. I really, really congratulate you all on trying to bring together all that we have discussed over the past couple of meetings so that we can walk through this in a very systematic, methodological way. I have two comments. No. 1, Ike, I agree 100% with everything that you were just mentioning, and my two comments are a little bit of an expansion of what you mentioned. This is not part of the framework, but part of the context of this entire roadmap, report, or element that we are going to produce is to clearly demonstrate the power of how we can utilize health technology to advance health equity and justice.

What I always like to say is that health information technology is the seventh social/structural driver of health, and that includes everything from interoperability to digital literacy and all those other items because if we do not utilize technology in the right way, we are not going to actually decrease all of those inequities that we continue to see within health and healthcare, community health, and population health. Once we put this all together, we need to really emphasize at the very beginning the importance of leveraging technology for this work so that anybody that picks it up clearly understands it.

The other piece that I was going to mention is that as we move forward, I know this is the framework and the guiding principles, but what I would also charge us with a bit is thinking about how we are going to practically demonstrate this to the reader. I can already clearly see where we are, and I think some of those examples that you showed, Hannah, were great examples. I think that what we may need to do as well is add some practical steps so that it is not just theoretical, but that we have examples of organizations or entities that have already done this, and also having…not an A-B-C-D, but almost like a Step 1-2-3, in order to get to that level. I think that will truly be able to meet that charge coming from ASTP right now of having that practical guide because we do know that the vast majority of organizations within our nation, while they want to do this work, while this is going to be fantastic to give them themes, subthemes, and guiding principles, we are still giving them some practical knowledge on how they can start or accelerate their journey.

I think as we think about the themes and subthemes, even when we say “incorporation of diverse participants and users in all the design,” how do you do that? We can say it, but we do not give examples of how to do that. I know we are probably going to go to the Google document, but that may be another area where, as we are looking at the themes and subthemes, we actually have a practical column as well to state how we recruit diverse participants and users to be involved in design, how we think about the community characteristics, and I would add “geographic” there. I know it says “settings,” but I would be very explicit about adding “geographic” as well in terms of diverse community characteristics. And then, we, from not only our area of expertise in this task force, can actually put what we have done in order to address these subthemes, but then we can also see where the gaps are, so that is where we can introduce more subject matter experts if we have not been able to clarify how to give those practical steps for those themes and subthemes as well. Again, I think this is a great, great start. I think we are all going to be able to zoom through this now and really appreciate structuring it in this way.

Hannah Galvin
Thanks, Medell. Those are great, great points. At a high level, we want this to be actionable. We want this to be impactful. To your points of having actionable, impactful steps for healthcare delivery organizations very specifically for ASTP, I think you are right on. This is exactly what we want to do. Thank you very much. Belinda?

ASTP

Belinda Seto
Thank you. I also want to add to Medell's comment that this is so well organized. It is really impressive work. I have two comments. First, I am going to start from the last section, harm and bias prevention. We ended with the last bullet of monitoring for and addressing algorithmic bias. I think we should go ahead and take it to the next level. Algorithms often are the basis that contributes to an artificial intelligence (AI) model, and so, I want to make sure that we do not just stop, but look at the algorithmic bias with the added bullet of ongoing validation of the AI model. For whatever reason, whether it is algorithmic bias, being one of them, or lack of transparency, if the AI model is no longer applicable, we want to know that when it actually happens, which requires us to monitor these AI models.

I was really impressed. I recently had my mammogram done, and it came back with a report clearly stating that the diagnosis was aided by an AI model. It is reassuring that it is augmentation of the care provider, but it clearly is now such a real thing, a real practice in healthcare. The other comment is on the bullet right above it, and I am influenced by the comment that this is really about healthcare and not research. As such, should we say "representative data for training emerging technologies" and leave out "research" so as to minimize confusion that we are really talking about healthcare?

Hannah Galvin
Great question, Belinda. First of all, I will say I absolutely agree with you. Algorithm vigilance is hugely important, and thank you for pointing that out. I think that is absolutely essential. I am interested in what the group thinks. As a clinician, I think it is incredibly important that we have representative data for research because I cannot practice evidence-based medicine if the research I am basing my evidence-based care on is biased, but I am interested in what others think. We do want to stay within the scope of our charge, but to me, that is within the scope of healthcare delivery. Medell?

Medell Briggs-Malonson
I actually agree with both of you, and maybe it is just a change of terminology. As a person who is a health services researcher by background and a clinician at an academic medical center, I definitely respect research, but I also know that it is important to highlight that we are looking at delivery care systems as well, and sometimes, they can be overshadowed by one or the other. I do think we need both, but even when it comes to artificial intelligence, what is fascinating in just watching the ecosystem and also being in both worlds of truly a large, complex health delivery system but also in the world of academia, I have noticed that sometimes, there is so much research that we are not thinking about the practical uses of our technologies just to provide everyday clinical care. So, maybe we should just modify something along the lines of "representative data to support clinical care and research emerging technologies."

Belinda Seto
[Inaudible – crosstalk] [00:31:44]

Medell Briggs-Malonson
Right, because we put clinical care very clearly as what we are trying to do, but we also need to have those foundations or research that also help us on the back end as well.

Belinda Seto
That is so well put, thank you. And then, I just have one last comment. I really support what Steven pointed out in terms of the foundational representation and the USCDI. In the first section, with inclusive representation, before even the first bullet of "diverse participants," I wonder if we should add a bullet before that to say "foundational representation," such as USCDI, for example.

Hannah Galvin
Foundational representation in data, you mean?

Belinda Seto
In data, yes.

Hannah Galvin
Foundational representation of these elements in data?

Belinda Seto
Yes.

Hannah Galvin
I like that because I was thinking of inclusive representation in terms of individual participants, but really, it is the foundational representation of the appropriate data elements.

Belinda Seto
Right, right.

Hannah Galvin
I really like that, Belinda. It is a slightly different way of thinking about inclusive representation, but it is incredibly important. I think it fits better there than in "transparency."

Belinda Seto
I think so too, yes.

Hannah Galvin
Excellent point. We are taking notes. Rochelle, you had your hand up. Did we cover your comment, or did you want to say anything additional?

Rochelle Prosser
It was covered a few times, and then something else came up, and that was covered. Belinda, thank you for restating what Steve said. I think it is a bit of both of what Steve is saying, that there is a foundation part to it, but we also need to understand the human element of it. We do not want to take that out of it because it will cause health inequities if we remove it. Is there any way we can represent it in both ways or come up with some line that reassures that, yes, it is the foundation of data, but what is attached to the foundation of data? It is the humanness of it and making sure that we have transparency of what that data is.

Belinda Seto
Oh, I agree. I do not mean to take out the participant. I only meant to add.

Rochelle Prosser
Yes. I am saying that maybe we can show it in a few places or come up with a way that does it, Beth. I think Medell is about to give us that answer.

Medell Briggs-Malonson
You are funny. I really appreciate and amplify also what Ike was stating. Ike, I do not want to put words in your mouth, but the way I interpret what you were stating is that we do not want people to have to recreate the wheel when we already have these standards in place that can be built upon, and so, part of what I was thinking is, even

when I was mentioning, for instance, the seventh social/structural driver of health and how this work is so important, there is also an element before we get into all the framework of saying, “And by the way, remember, we have USCDI, we have all these other elements that are already looking at this to help to streamline the work on incorporating health equity by design into health technologies, protocols, data analytics, and also into artificial intelligence or whatever that may be. We have the foundational element already, and here is the list of them of you to keep in mind and consider as you are incorporating these principles into your work.”

That is how I interpreted what you were saying. I completely agree because, as I can tell you, even doing this work in my organization, we just did it without necessarily truly aligning as much with USCDI and some of the other elements that we should have from the very beginning, and we would not want others to have some of those missteps. So, Ike, that is how I took your comment, and that is just my idea of putting and having some of that language and contextual background up front so that the reader is very clear about what tools they already have, and then going into our framework and other items.

Steven Eichner

Exactly. If you will, we have a bunch of Lego pieces in a bag that we can start to build. It may not already exist as a structure, but we have this bag of resources that we can use. How do we put them together? Do we need a couple of new pieces? Do we need to get an extra Lego set because there is a really special piece that we do not have in our bucket already? Okay, let’s get another bucket. But if we do not understand what pieces wee have to work off of, we are making life harder than it needs to be for people who are not as familiar with some of the things that are already out there. That was my thought.

Medell Briggs-Malonson

That also aligns with what we are trying to do through ASTP as well and all the work ASTP has pushed through. I love that idea, Ike.

Hannah Galvin

That makes a lot of sense. Any other comments? Are there subthemes here that you think need to be reworded or should not be subthemes?

Derek De Young

I am raising my hand, but I am the only one with my hand raised, so I am just going to start talking.

Hannah Galvin

Please, Derek.

Derek De Young

As I read through this again with a fresh look, for privacy, maybe in the last one, “harm and bias prevention,” there are pros and cons data segmentation, and I want to make sure we are thinking about both sides. I was wondering if it should be privacy and patient **[inaudible] [00:38:59]** either recommending or implementing data segmentation. If that patient moves somewhere else and a clinician does not have access to that data, what do they need from a patient safety standpoint? Could that impact that patient’s care the next time they go somewhere if that provider does not have access to that crucial piece of information that could have impacted that patient’s care because that person did not want that one piece of data sent? Again, it all depends on what our definition of data segmentation is. Is it a specific diagnosis and a problem list, or is it something broad? Every time I see “data segmentation,” I like to bring that up just to make sure that they are aligned and we know what we are talking about when we think about data segmentation. **[Inaudible] [00:39:52]** do that.

Hannah Galvin

Derek, that is a really good point, and I know Matt Doyle has been Epic's representative to Shift in the work that is going on there. I will just give my thoughts on that, though not as the co-chair of this group. Any discussions around data segmentation have to be very thoughtful and nuanced. It is not that we just recommend going forward with data segmentation. Some of the discussions that have been going on at Shift around this include if you are going to allow patients to consent to share their data and drive how their data is shared, what are the safety implications of that, how should there be informed consent, how should you understand the risks or benefits for what that would be, and how should data segmentation be allowed or not allowed for things like research?

There are limitations. If I say I do not want to share my reproductive health data with this institution in Texas, for instance, because it might be criminalized, that may improve equity in some situations because now I feel more comfortable sharing that with my provider in Massachusetts, where I otherwise might not share it because I am worried about how that data is going to be shared, but it may also decrease equity because it may increase harm if I go to Texas, they do not have that information, and I show up bleeding, then there may be concern there. It may also cause equity concerns because what if they are training an AI algorithm at that institution, they do not have my data, and it leads to algorithmic bias? Any of those discussions are incredibly complex and nuanced and cannot be a black-and-white yes, we support data segmentation or no, we do not support data segmentation.

So, I agree with your point 100%, Derek. I think the example that I gave two slides down was something like "fund more work around this," but not "our recommendation is that everybody should be able to segment their data." If we need to reword that in some way, we can decide. Maybe we do not even want to have that on there. I think we captured that from multiple conversations here and at the broader HITAC. I think everybody knows that is my passion project, but that does not mean it should go on this list if the task force does not think that it should, but if it should, it has to be discussed in the appropriate context, which is that this is a very complicated discussion around which a lot of work needs to be done.

Derek De Young

I fully agree. It is incredibly nuanced and very complex. In terms of a wording change, maybe that is something small, maybe "appropriate data segmentation" or "thoughtful and appropriate data segmentation and consent" or something like that, just to make sure that people who are reading this understand that this is not for everything. We want to be very careful with what can and cannot be done and make sure it is appropriate and equitable.

Hannah Galvin

I like that. I do not know how others feel about that. There is a lot of work to be done to ensure that any type of data segmentation would be safe and appropriate, so I support that. Medell?

Medell Briggs-Malonson

I have a quick question. Thank you both for that conversation. I am wondering if that would be more underneath the area of recommendations for ASTP at this moment, looking into and still thinking through the thoughtful data segmentation versus what we are offering as a practical guide to our organizations. The only reason why I mention that is that a lot of these different items, at least when we have two sets of recommendations, relate both to health service organizations as a practical guide and also to ASTP as they function in their role coordinating authority. I do not know if, at least in this current state when this comes out, our individual health service organizations are able to segment their data yet. I a just bringing that up, and it is more of a question because if they are able to unable segment their data themselves right now, though we know it has all of the different benefits and that it has to be done the right way, is this, again, just solely in that ASTP recommendation column?

Hannah Galvin

I tried to highlight that, Medell. Accel team, could you skip down to Recommendation No. 2? I do not think that we necessarily need a No. 1 or a sub-recommendation for every single one, but if we were going to do one for this

one, where it is not that actionable for health delivery organizations yet, it could be something relatively general. We might recommend that patients be allowed to indicate that they prefer their data not be shared. That does not mean that there is the technology yet to really act on that indication in many situations or to act on it in a non-all-or-none manner, but we may or may not think that is reasonable to say, but there is not a great technological solution for this yet. The biggest part of that recommendation would be that ASTP fund ongoing work. We might decide that No. 1 is just not actionable enough to even make as a recommendation. So, that is what I tried to do here to show that we might have a very high-level recommendation that patients should have some ability to let you know if they do not want to share this data, even if you cannot act on it yet. I think this is very true. We may not have a recommendation for both Bullet Points 1 and 2 for each one of these. Ike?

Steven Eichner
In that same context, we need to be really careful about how our recommendations may be perceived as being implementable and by whom they are implementable. In this particular case, looking at Option 1, great, I can indicate that my data should not be shared, but without the supporting technology to actually activate or utilize my indication, I have not exactly built up trust with my patient or the patient population in terms of doing whatever it is. So, this is specific to this particular potential recommendation, but I think the bigger piece is that we need to put the right caveats in place about how these things are recommendations. Everything might not be implemented in every circumstance.

Mileage may vary a little bit in terms of what individual providers may or may not do, but we kind of need to include… As a general component, I am also in favor of making recommendations that address public health as well, not necessarily in terms of privacy components, but there was another one we visited a little bit ago related to race and ethnicity data. Actually, I was on a call just prior to this one talking about race and ethnicity data collected as part of immunization reporting, so I think that is more of a state and local thing than a federal thing, but there is another set of actors that should be at the table.

Hannah Galvin
Absolutely, and I think that is part of what we are going to talk about as we go forward into recommendations. We may not want to give a recommendation here that is not actually…

Steven Eichner
I am saying that holistically, as Medell will appreciate from other conversations in other topics, that state, territorial, and local health departments are important actors in a variety of tools and need to be recognized as a community of public health. It is not solely CDC. The State, Tribal, Local, and Territorial (STLT) are separate actors.

Hannah Galvin
Good point. Accel, can you go back up two slides so we can take a look at the themes again? Great. Any other thoughts on the themes? That was a really good one, Derek, and exactly what we need. How should we hone the language? How should we wordsmith this so it is appropriate? Between now and next week, we really need to solidify the framework. The framework needs to be there, the themes and the subthemes, so that we can start going through one by one and making recommendations because I just want to outline for this group that we have January to mid-February if we need to have anybody else come in and give some expertise that is not in this group. That is great. But then, we will have a month afterward, really, to get our recommendations together, and we are running up against this. This is going pretty fast. Ike?

Steven Eichner
Sorry, you already covered it.

Hannah Galvin

We already covered it? Okay. I see a note in the chat about some potential duplication, about diverse participants involved in the design, as well as diverse use cases and real-world testing across diverse use cases. We tried to differentiate between diverse participants and diverse use cases. There is diversity in participants and community characteristics and in use cases, but if there is a thought about tightening that up, that would be great. I cannot see who put that in the chat. Karolina? If you want to speak to that further, that would be great. You can raise your hand. Janée?

Janée Tyus
Under transparency, I think we also need to say something about the use of the data. I know we have diverse use cases and local needs under it being inclusive and representative, but I think there should be a point in there, which I guess would be a subtheme, that relates to transparency regarding the use of data and its purpose, I guess. Does that make sense? I might not be clear.

Hannah Galvin
Transparent purpose of use, yes.

Janée Tyus
To that point, I think it recognizes or acknowledges that people own their data, so there should be transparency in folks being able to see what that stuff is going to be used for beyond the data set.

Hannah Galvin
Yes, and I do not know whether we can advise ASTP. In 21st Century Cures, I think ASTP has really outlined that the data belongs to the people, and there is that paradigm shift. I do not know if that is aligned across all federal legislation. For instance, Health Insurance Portability and Accountability Act (HIPAA) still requires that if I want to not disclose my data and have control over my data, as a patient-requested restriction on disclosure, I have to request that of the covered entity that holds my data. I think there could be room here for some ask of ASTP and their coordinating entity to work with Office for Civil Rights (OCR) and other federal agencies to align around legislation because I think there is still some question about who the data belongs to legislatively, anyway, but Janée, I think that is a great point, and if our perspective is to make the data belong to the people, HITAC should make that perspective known. Ike?

Steven Eichner
I have organized my thoughts now. Under inclusive representation right now, we have a last vote that is needed for sustainable workforce. I think we might want to spin that out, create another theme, and have something like “a skilled workforce” or “a knowledgeable workforce,” crosscutting issues being tied to what is going on in space right now around workforce issues and representation and components. It might be better to address it to ensure that we have a workforce that is knowledgeable about race and ethnicity issues as a theme.

Hannah Galvin
So, a skilled, sustainable workforce knowledgeable in issues related to health equity?

Steven Eichner
Correct.

Hannah Galvin
Yes, which sort of fleshes out that point a little bit more.

Steven Eichner

Moving it over so it is not focused on a workforce that is necessarily represented, but focused on the components of what concepts are part of the workforce that need to be involved, which are the target components: The skills and knowledge around race and ethnicity issues.

Hannah Galvin

I love it. Let's capture that. Any others? These are great comments, everyone. They are very helpful. Seth, Whitney, Arina, or Mark, we are probably going to put this in a Google doc so that people can comment dynamically, right? What format are we going to have this in so that we can get comments?

Steven Eichner

Hannah, this is Steve again. Looking under harm and bias prevention, particularly at the first component, addressing systemic and structural upstream drivers of health inequities, I am not at all suggesting that that is not an issue in addressing health equity, but thinking about it from a technology/health IT kind of component, just thinking about what kind of recommendation is health-IT-focused in that space, I am at a little bit of a loss.

Hannah Galvin

That is a really good question, Steve. I think it was captured directly from Tom Mason when he spoke, although, Mark, Seth, or others, please correct me if I am wrong. We may want to circle back with him. There was some thought that this blueprint would want to…

Steven Eichner

Answering my own question, I could certainly see using technology for helping refer folks, both bidirectionally and as an element.

Hannah Galvin

So, we added improving access to care. We may end up finding that if we think about some of the process measures that come from this, they each fall into a subtheme and we can remove that kind of higher-level subtheme, but I think we wanted to include it very specifically as a thought point. In and of itself, it might not need to be something… So, as we think about it this week, perhaps we can think about some of the ways that we can do this more specifically to call out that it might be more generative of specific recommendations than this kind of higher-level point.

Steven Eichner

I guess the buzzwords may be "systemic and structural drivers" versus looking at addressing drivers of health and equity. In other words, in our scope, looking at systemic change may be difficult because most of what we are talking about doing is effectively acting more on the individual level rather than on a national level.

Hannah Galvin

As we talk about having representative data for AI, I can see how that can address some of the systemic and structural drivers. As we look at the population level and address things like chronic disease at the population level, that can help address some of the systemic and structural drivers for populations and those types of things, but we may want to call those out individually as opposed to having such a broad subtheme there, as you indicated. Medell?

Medell Briggs-Malonson

I hear the conversation here, and I am recalling that the idea of addressing systemic and structural factors that result in racism, discrimination, and other forms of bias that result in health inequities was the goal of looking at harm and bias prevention, especially those that are already embedded in technology, and there have already been numerous different, even clinical, algorithms that have been based in medicine for a very long time. We do not

have to go over all of those with everyone here, but, for instance, estimated glomerular filtration rate (eGFR) is a perfect example of something that was rooted within our clinical and lab technologies which resulted in clear racial health inequities not only in our country, but across the world, and it is only now that we have taken steps to remove those items, which was very structural and very systemic, that we are slowly seeing resolution of those health inequities.

I think that was the whole point of this bullet. When we are thinking about harm and bias prevention, we should take a step back and look at the current state of our technologies, clinical algorithms, or whatever we are using, and questioning the oftentimes very poor evidence that has driven us to incorporate some of those elements into our technology so that we can remove them so we do not have racialized medicine or medicine that discriminates based on one's identity. I think that is where that came from, and even now, on this bullet, I was just going to put my comments up this week. We should really land on whether we are going to address inequities or disparities because those two items are different, so we should really recommend that we as a task force should land on one term or the other. I always highly recommend "inequities" because inequities are rooted in injustices, and disparities may not be rooted in injustice, they may just be differences that are totally appropriate, such as shoe size. But I want to make sure we are using a common terminology, again, so that we do not mix some of these different terms together because they are actually not synonymous.

Steven Eichner

I very much appreciate what you said. I think I got hooked on the word "upstream" in there. I may have put too much value on that word, thinking about… So, what changes can we recommend here about upstream, systemic changes? That is where I was kind of stuck. I thoroughly appreciate looking at changes within the health sphere writ broadly. I put too much emphasis on that one word.

Medell Briggs-Malonson

That makes sense too, and that "upstream" piece there might be something to clarify because there are upstream factors, as we know, but is that going to be within the scope of this approach, of what we are trying to do? I understand exactly what you are referring to, Ike. We talk all the time about the upstream factors that contribute to both poor and really good health outcomes, but what is the true definition of what we are saying when we talk about systemic and structural drivers and factors within the scope of health technology right now? I completely hear you on that.

Hannah Galvin

All right, thank you. I did get a question in the chat about going to the spreadsheet. This was the summation of everyone's comments from the spreadsheet, so, just to let everyone know, we are not planning to go back to the spreadsheet today. We are going to then take this and put it in a different spreadsheet format for people to edit further so that it is available and we can get your comments and feedback on it, but we were not planning to go back to the homework spreadsheet. We took all the comments that came in from that spreadsheet, amalgamated them, and tried to align them into this framework, just for clarification. All right, any other comments or questions?

Steven Eichner

I am going to make one more friendly suggestion. Instead of looking at inclusive representation, what happens if we change it to inclusive participation?

Hannah Galvin

Should we use "participation" instead of "representation"?

Steven Eichner

Right. It is not so much looking at a checkbox approach: "Do I have somebody from X population sitting at the table?" It is really about involving expertise, I think.

Hannah Galvin
I think that is a proposal that can certainly be made. What do others think?

Medell Briggs-Malonson
I am trying to be quiet, everyone, so I will wait. Well, I will just jump in really quickly. I love what you are trying to get at, Ike, because what you are really talking about is true inclusivity and inclusive excellence. It is not just about the peer representation, it is about the representation, participation, and thought leadership. I am wondering if it is both because in terms of our data, our data will be more underneath that inclusive representation, but when it comes to our participants that are involved in the design, governance, and sustainable and inclusive representative workforce that is active, that is participation. You are absolutely right. It is not just about saying we checked a box, it is about how everyone is at the table in the design, monitoring, and governance, and that is very action-oriented participation versus just representation, so maybe it is inclusive representation and participation, and all of those different elements come underneath it because I do think you are correct. It is not about being passive and saying we have people at the table, but yet, not everyone at the table has a voice.

Hannah Galvin
Medell and Ike, I like that, and in the fact that we have talked about including data in this, I think you make a really good point, Medell, that data is not participatory, but I think calling out how to avoid tokenism is really important because I do think that that is a trap that many groups and organizations run into. "Let's just have some diversity at the table, whether or not it is the right person, the right role, or whatever. We are just checking that box." I think calling that out very specifically in this area and giving some recommendations on how to promote participation is one of the things that ASTP is looking for us to do here to really be impactful. To a point in the chat, compensation is sometimes available and sometimes not available, and I think many of us on the call have had lots of diverse experiences with how to bring the right voices to the table and can offer some real-life suggestions there. Those are really excellent points, so we will make some of those adjustments. Any other thoughts? Why don't we go to next steps, and then we have public comment coming soon. We can skip down. Seth, did you want to go to public comment first, and then come back?

Seth Pazinski
No, we still have five minutes until we need to go to public comment.

Hannah Galvin
All right, so, why don't we talk about next steps? Seth or Mark, can you remind me about the framework? Are we going to put it in a separate tab in the Google sheet? How are we going to service it to everyone? A new Google sheet?

Mark Savage
Hannah, this is Mark. I have been taking notes on the themes that were on the sheet. I have not been editing. Instead, I have just been capturing the ideas so that the task force can make some decisions about what to do, but it is there, and you can decide whether you want to circulate that with the comments and have others add their comments or whether you want to make any changes and then put that up, but anyway, it is one of the tabs in the Google sheet, and the notes are already captured.

Hannah Galvin
Thanks so much, Mark. All right, we will take a look at it and circulate it as a tab in the Google sheet. I did get a couple of private comments that some may have added comments to the previous sheet right at the end which

were not captured, so if you have previous comments, you can copy them over. We will be working off this framework going forward. The ask for this week is to take a look. We are going to send it out. Are there missing or suggested edits? Mark has captured some of the notes. Please endorse them or edit them further as edits to the framework. When is our meeting next week? When is the internal meeting?

Seth Pazinski
The next task force meeting is next Wednesday the 18th.

Hannah Galvin
Before our internal meeting? So, we will probably give you guys a deadline so that we can circle back up internally, put all of your thoughts together, and present this for the task force next week because at the task force next week, we are really going to want to vote on a final framework so that we can move forward, so we will send it out later today, and probably by Friday or the end of the day on Monday, we will talk about it internally. We will ask for any comments on the themes or subthemes and any suggested edits in relatively short order. The reason is that we need to then circle up and make any edits to present it to you on Wednesday as a final version for voting, "This is our framework, this is the framework we are going to be working with," and then move forward. Steve, we will send it out as well.

We need to start moving ahead here. As you see, we have a relatively short timeline. The other thing we will ask you, probably in a separate column on the Google sheet for each of the themes and subthemes, is if you do not think we have the expertise right here on the task force and you think we need a presentation by a SME to help us develop the recommendations, please also indicate that because we have to start booking the SMEs in for January, really, because we need to complete all the presentations by mid-February at the latest. We want to be really strategic about our use of SME perspectives, especially for very specific or technical considerations of which we might not have the expertise here among our diverse group to speak to, so if there are any areas where we really feel we need somebody, please also indicate that. We will make sure there is a place for you to indicate that. So, there is a lot to do between now and the deadline we will give you. We will let you know. It will probably be Friday or Monday so we can make sure we can move this along and meet our deadline and requirements. Any questions about that? All right, Seth. I will turn it over to you.

Public Comment (01:15:29)

Seth Pazinski
All right, thank you. We are going to move into the public comment portion of our agenda for today. Thank you, Accel. If you are on the Zoom and you would like to make a comment, use the hand raise function, which is located on the Zoom toolbar at the bottom of your screen. If you are participating by phone only today, you can press *9 to raise your hand, and, once called upon, press *6 to mute and unmute your line. As we give the public a few minutes to raise their hands, I just have a couple reminders. As I mentioned, the next Health Equity by Design Task Force meeting is going to be a week from today, Wednesday, December 18th at 1:30 to 3:00 p.m. Eastern Time, and, as a reminder, all the meeting materials from today's meeting are available publicly on HealthIT.gov. I am not seeing any hands raised within the Zoom, and there are none on the line as well, so, Hannah, I will give it back to you to close us out.

Next Steps (01:16:41)

Hannah Galvin
Thanks so much, everyone, for your continued valuable expertise, participation, and engagement in this important work. It is so valuable. As we know, this is the first time that ASTP is doing something like this, and this is incredibly important work that we are doing. The comments today have been incredibly valuable, and the work you

are going to be doing between now and next week to really help us edit and finalize this framework and recommend any subject matter expertise is also incredibly valuable so that we can set the stage for setting ourselves up for making these recommendations. As Accel is showing on the screen, the first time we present to the full HITAC is at the next HITAC meeting on February 13th, so things are moving pretty fast, and we are really excited about it, and I really am just very appreciative to all of you for your collaboration and lending yourselves to this really important work. So, thank you. We will see you next week.

Belinda Seto
Thanks for organizing and leading us.

Hannah Galvin
Thanks. It is my pleasure.

Adjourn (01:17:59)

Questions and Comments Received Via Zoom Webinar Chat

Rochelle Prosser: +1Belinda

Rochelle Prosser: +1 Hannah

Rochelle Prosser: Well said Medell

Sarah DeSilvey: + 1 all. This makes a lot of sense as a common essential tool.

Medell K. Briggs-Malonson: +1 Ike. Yes, we need to inclusive of all of our service organizations.

Sarah DeSilvey: + 1 Janée

Medell K. Briggs-Malonson: +1 Janee! The data of the people belongs to the people

Sarah DeSilvey: +1 Medell

Rochelle Prosser: This is a good start for the group

Steven Eichner: +1 Medell

Steven Eichner: I will be unable to attend next week's meeting.

Questions and Comments Received Via Email

No comments were received via email.

Resources

Health Equity by Design Task Force 2024

Health Equity by Design Task Force 2024 - December 11, 2024, Meeting Webpage

Transcript approved by Seth Pazinski, HITAC DFO, on 12/20/24.