Transcript

HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC) MEETING

March 10, 2022, 10:00 a.m. – 4:45 p.m. ET

VIRTUAL

Speakers

Name	Organization	Role
Aaron Miri	**Baptist Health**	**Co-Chair**
Denise Webb	**Individual**	**Co-Chair**
Medell Briggs-Malonson	UCLA Health	Member
Hans Buitendijk	Cerner	Member
Steven (Ike) Eichner	Texas Department of State Health Services	Member
Cynthia A. Fisher	PatientRightsAdvocate.org	Member
Lisa Frey	St. Elizabeth Healthcare	Member
Rajesh Godavarthi	MCG Health, part of the Hearst Health network	Member
Valerie Grey	New York eHealth Collaborative	Member
Steven Hester	Norton Healthcare	Member
Jim Jirjis	HCA Healthcare	Member
John Kansky	Indiana Health Information Exchange	Member
Kensaku Kawamoto	University of Utah Health	Member
Steven Lane	Sutter Health	Member
Leslie Lenert	Medical University of South Carolina	Member
Hung S. Luu	Children's Health	Member
Arien Malec	Change Healthcare	Member
Clem McDonald	National Library of Medicine	Member
Aaron Neinstein	UCSF Health	Member
Eliel Oliveira	Dell Medical School, University of Texas at Austin	Member
Brett Oliver	Baptist Health	Member
James Pantelas	Individual	Member
Raj Ratwani	MedStar Health	Member
Abby Sears	OCHIN	Member
Alexis Snyder	Individual	Member
Fillipe Southerland	Yardi Systems, Inc.	Member
Sheryl Turney	Anthem, Inc.	Member
Thomas Cantilina	Department of Defense	Federal Representative
Adi V. Gundlapalli	Centers for Disease Control and Prevention	Federal Representative
Ram Iyer	Food and Drug Administration	Federal Representative

Jonathan Nebeker	Department of Veterans Health Affairs	Federal Representative
Michelle Schreiber	Centers for Medicare and Medicaid Services	Federal Representative
Ram Sriram	National Institute of Standards and Technology	Federal Representative
Micky Tripathi	Office of the National Coordinator for Health Information Technology	National Coordinator
Steve Posnack	Office of the National Coordinator for Health Information Technology	Deputy National Coordinator
Elise Sweeney Anthony	Office of the National Coordinator for Health Information Technology	Executive Director, Office of Policy
Avinash Shanbhag	Office of the National Coordinator for Health Information Technology	Executive Director, Office of Technology
Michael Berry	Office of the National Coordinator for Health Information Technology	Designated Federal Officer
Tammy Banks	Individual	Presenter
Eboné Carrington	Manatt Health	Presenter
Kathleen Blake	American Medical Association	Presenter
Irene Dankwa-Mullan	IBM Cloud and Cognitive Software	Presenter
Ziad Obermeyer	University of California Berkeley	Presenter
Nicol Turner Lee	Brookings Institution	Presenter
Terri Willits	Anthem Inc.	Presenter
Denise Hines	Georgia Health Information Network	Presenter
Dominic Mack	Morehouse School of Medicine	Presenter
Angela Thomas	MedStar Health	Presenter
Andrew Hamilton	AllianceChicago	Presenter
Janet Campbell	Epic	Presenter
Robert Murry	NextGen Healthcare	Presenter
Jaffer Traish	findhelp	Presenter
Carlos Felipe	Unite us	Presenter
Read Holman	Unite us	Presenter
Trenor Williams	Socially Determined	Presenter

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

Mike Berry
Good morning, everyone. I am Mike Berry with ONC, and I would like to thank you and welcome you to the March 2022 HITAC meeting which features the health equity by design hearing. We are very excited you are with us today and as a reminder, your feedback is always welcomed which can be typed in the chat feature or made verbally during the public comment period which is scheduled at 4:30 eastern time this afternoon. So, let us get started with our meeting.

First of all, I would like to welcome ONC's executive leadership team to the meeting and with us today is our National Coordinator, Micky Tripathi. Steve Posnack, the Deputy National Coordinator, and Elise Sweeny Anthony, the Executive Director of the Office of Policy, and Avinash Shanbhag, the Executive Director of the Office of Technology. I will now call the meeting to order and begin the roll call of the HITAC members along with the federal agency representative of the HITAC. When I call your name indicate you are with us. Let us start with our co-chairs, Aaron Miri.

Aaron Miri
Good morning.

Mike Berry
Denise Webb.

Denise Webb
Good morning.

Mike Berry
Medell Briggs-Malonson.

Medell Briggs-Malonson
Good morning.

Mike Berry
Hans Buitendijk

Hans Buitendijk
Morning.

Mike Berry
Thomas Cantilina. Steven (Ike) Eichner

Steven (Ike) Eichner
Good morning.

Mike Berry
Cynthia Fisher. Lisa Fry. Raj Godavarthi.

Raj Godavarthi
Good morning.

Mike Berry
Valerie Grey.

Valerie Grey
Good morning.

Mike Berry
Adi Gundlapalli.

Sanjeev Tandon
Sanjeev Tandon for Adi. Good morning.

Mike Berry
Thank you, Sanjeev. Steven Hester. Ram Iyer. Jim Jirjis. John Kansky.

John Kansky
Good morning.

Mike Berry
Ken Kawamoto.

Ken Kawamoto
Morning.

Mike Berry
Steven Lane.

Steven Lane
Hello.

Mike Berry
Leslie Lenert. Hung Luu

Hung Luu
Good morning.

Mike Berry
Arien Malec.

Arien Malec
Good morning.

Mike Berry
Clem McDonald. Jonathan Nebeker. Aaron Neinstein.

Aaron Neinstein
Here. Good morning.

Mike Berry
Eliel Oliveira.

Eliel Oliveira
Good morning.

Mike Berry
Brett Oliver.

Brett Oliver
Good morning.

Mike Berry
James Pantelas. Raj Ratwani.

Raj Ratwani
Good morning.

Mike Berry
Michelle Schreiber.

Michelle Schreiber
I want to note that Alex Mugge will be taking over for the CMS representative after 12:00 p.m.

Mike Berry
Thank you, Michelle. Abby Sears. Alexis Snyder.

Alexis Snyder
Good morning.

Mike Berry
Fil Southerland. Ram Sriram.

Ram Sriram
Good morning.

Mike Berry
And Sheryl Turney.

Sheryl Turney
Good morning.

Mike Berry

Good morning to all. Thank you so much and now, please join me in welcoming Steve Posnack for his opening remarks. Steve?

Welcome Remarks (00:03:29)

Steve Posnack

All right. Good morning and welcome to the March HITAC. I know it has been a while since you have seen me on camera. Still bald. Like many of you my family got a dog during the pandemic and the last time I tried to give opening remarks, I tried the treat option to distract him, which backfired because he then brought it over to my desk and barked at it while I was giving remarks. So, this time around, I am going to do the ignore and not make eye contact approach and see how well that works.

We have, as we stated, an action-packed agenda planned for you today, including the Health Equity by Design Hearing which will start promptly at 11:30 a.m. ET. The hearing portion of the meeting features a rock star lineup; guest speakers, each of them has a passion for promoting health equity and we are very pleased to welcome them to our HITAC meeting.

Before we transition to the hearing portion of today's agenda, Sheryl Turney and Tammy Banks, who have been leading a very quick electronic prior authorization request for information task force will present their recommendations to the HITAC. I really want to note two things, 1.) The request for information period is still open until March 22nd, so for those of you that procrastinate, now is the time.

And then, 2.) It is also important for the HITAC to finalize its recommendations today so they can be transmitted in a timely manner to the national coordinator. Sheryl and Tammy, along with the task force, have been working diligently the past seven weeks to answer questions outlined in the RFI, and on behalf of the ONC, we are appreciative of the time, effort, and expertise of the members of the task force has brought to the table to develop the recommendations. As you all have been through this before, it is quick, fast-paced. Requires a lot of just insight ingenuity and creativity how to get those responses put together in the short period of time you have, and you have risen to the occasion again.

And then last but not least, our frequent members of the presentation to HITAC, Steven Lane and Arien Malec will provide a brief update on their progress to date of the interoperability standards worker.

Just a few updates to cover from an ONC perspective as well, in case you missed it, we released a new data brief and information data set on information blocking claims that we have received through the information blocking portal since April 5 of last year. Which was the applicability of the information blocking regulation. This also has accompanied a blog post that includes a bit of additional information, explanation, insights that we have been able to glean from the data that has been submitted thus far. And so, it includes a submission on the number of basic stats on cumulative amounts of information that we have received and that we have been able to parse through from the information blocking submissions and they are stratified by several different ways the team has dug into that.

We will also be providing, we anticipate, updates on a pretty regular basis. So, we will be able to trend this over time and again, this is one of those commitments transparency that we have concerning work that we do. More information about information blocking in general. We have several FAQs; we have fact sheets

and other process flow diagrams that include what happens to a claim once submitted. That covers the different authorities and oversight responsibilities that both ONC and the Office of Inspector General have with respect to information blocking. So again, all of those can be found at health IT.gov. I also hope that you had a chance to read Micky's article on health affairs entitled, "Delivering on a Promise of Health Information Technology in 2022." Spoiler alert, 2022 is going to be a big year from our perspective and we are glad you are along for the ride.

So, the last couple of points, I want to remind everyone to please join us for annual meeting round two on April 13th and 14th where we plan to host panel sessions to discuss health IT and health equity, public health, patient access, and patient advocacy, as well as health information exchange. The important bit for all of you: the registration is now open. So, please go ahead and get that. It is virtual so you can do it from your couch, your home setup du jour, or wherever you prefer to check in on these annual meeting events.

You may have noticed if you are attuned to the HITAC calendar that HITAC also is going to be on April 13th. So, we will be working with you all to make sure that we have an optimized agenda. We are planning to start at 9:30 a.m. ET, but we do plan to shorten the meeting a bit to make sure that it ends on time and there's no overlap with the second half of the day from the April 13th perspective. In closing, I would love to thank everybody for joining us today and look forward to the conversation and the hearing which is going to be super interesting. And I will turn it over to Aaron and Denise to begin the business of the HITAC. Thanks very much.

Opening Remarks, Review of Agenda and Approval of February 17, 2022 Meeting Minutes (00:08:39)

Aaron Miri
All right, Steve. Thanks so much for those comments and welcome everybody to this month's agenda and this month's opening festivities as Steve was saying so it should be quite exciting. Denise, anything you want to add?

Denise Webb
I just want to say good morning and thank you for attending today, including our public, and thank you in advance to all of our presenters and especially those providing testimony today.

Aaron Miri
Yeah.

Denise Webb
So, with that, I could start with the agenda.

Aaron Miri
I want to say one more thing. I will say, Denise, that I am super excited about the health equity component. All of the topics here today are great, but this hearing is going to be really off the charts looking at the speakers, the topics, and the agenda. I can tell you that even at the AHA meeting last week, the event that was going on this week in Miami and the event going on next week in Orlando, health equity is a huge component of everything we are doing and talking about. So, talk about relevancy and timeliness for such a topic.

And I want to say the second thing. I want to give a lot of credit to ONC I thought the information blocking information, say that three times fast, that was released publicly was very interesting. The number of items that have been submitted. Steve alluded to that. So, if you have not seen that, please take a look at that and you can get an idea for it.

And last but not least is the plug for the October deadline of EHI, the full definition of EHI as I was talking about the last meeting which all of us especially on the provider side must present and allow for all of the information to flow back to a patient that belongs to them both within the EMR and outside of the EMR. So, start now if you haven't started looking for that. All right, that was my soapbox, Denise. Let us go into it.

Denise Webb:
All right. Thank you, Aaron. I am pleased that our committee and with the help of ONC can conduct this hearing today on health equity by design. We are going to have a packed agenda today. Let me briefly go over the agenda. We will conduct our normal HITAC business and presentations starting with the presentation of recommendations from the e-Prior Authorization Request for Information Task Force from Sheryl Turney and Tammy Banks. And then we will hear from Steven Lane and Arien Malec, the co-chairs of the Interoperability Standards Workgroup for an update. And then we are going to take a break and after the break, we will start the hearing. I just want to say a few things about how we are going to conduct the hearing.

Before each topic, we are going to give a very brief introduction of who is speaking before we start the topic. And if you are interested in more detail about the presenters, bios were e-mailed to the HITAC members and will be available on health IT.gov after the meeting, as well as the testimony, and slides. Each speaker will have a set amount of time, we will be reminding speakers of that. And then we will have some moderated discussion after each topic.

The topics that we are going to be hearing about this morning will kick off with Health Equity by Design, hearing opening remarks from Micky Tripathi. And then following that, we will have Framing of the Problem. Then a discussion. Then we will go into the use of Data, Artificial Intelligence, and Machine Learning Systems Integration and Interoperability, and then a discussion, and then we will take a break. After the break, we are going to have two parts on Content and Exchange of Data, Part I and II. And between those two parts, after our discussion on the first part, we will take a break. And then when we conclude Part II of content and exchange of data, we will have some discussion and then we will go to public comment. So, we have a jam-packed day today.

I ask all of our presenters that are providing testimony today to please try to stay within your time limit out of respect for the other individuals who will be presenting. And we will remind you if you are running over time. So, with that, I think we are ready to do a vote or approval of our minutes. I'm going to turn that over to Aaron and he will take it from there.

Aaron Miri
Absolutely. Thank you, Denise. All right. So, hopefully, you all had a chance to look over the minutes from the last meeting and you have had a chance to just review, peruse, and update yourselves. So, may I get an initial motion vote to approve, please.

Medell Briggs-Malonson
This is Medell Briggs. So, moved.

Aaron Miri
Wonderful. May I have a second?

Jim Jirjis
Second.

Aaron Miri
All right. All those in favor, please say aye.

[Chorus of aye]

Aaron Miri
Those opposed say nay. And any abstentions. Okie dokie. So, those minutes are approved, Denise. And so, I think we are ready to get the show going with Sheryl Turney and Tammy Banks.

e-Prior Authorization Request for Information Task Force: HITAC Discussion and Vote

Sheryl Turney
Thank you so much, Aaron. I appreciate it. And I want to just start by thanking ONC and Accel and everybody that volunteered for this task force. It was a rapid-fire event and I think everybody came together very well. So, can we go to the next slide? We are going to just quickly review our charge, the membership, the process and then really focus time on the recommendations and discussion. We can go to the next slide. Then go to the next slide.

This was the charge and I just do want to quickly review it because some things were related but not necessarily within scope. But we were responding to the RFI that came out recently on the electronic prior authorization, and the charge was specifically to provide input recommendations on the questions. The topics that were included in that RFI would help ONC in their consideration of an IT certification program, and for incorporating standards of certification criteria related to electronic prior authorizations. We can go to the next slide.

This was the group of individuals that participated and really, we had active participation by everyone; and again, not noted here is ONC staff and Accel who supported us very, very well and I wanted to call that out again. So, we can go to the next slide.

The process we followed, we highlighted some of this last time, but essentially, we reviewed the charge, the RFI, the scope. We discussed the questions, created a Google Doc with each of the questions, and gathered a lot of discussion from the group as we reviewed each item. We tried to group these items by type. We identified that we needed some additional subject matter expertise on the task force, so we secured those. We invited additional individuals to come and speak so that there would be at least a common understanding for those that were not intimately familiar with the three implementation guides referenced in the RFI: Coverage Requirements Discovery, Documentation Templates and Rules, and Prior

Authorization Support. All three are key to making an electronic prior authorization work and overlaying that on a system where they may not all exist the capabilities in one EMR system.

We had John Kelly come and talk about the attachment standards and then Hans from HITAC was kind enough to come and presented an overview of the health IT electronic prior authorization landscape and really, sort of mapped it to the implementation guides. Also, we looked at it in terms of a bundled process and you, hopefully, got that from reading the report as well. You can go to the next slide. We also then focused on summarizing the comments, reviewing the questions, and compiling and reviewing the regulatory resources. We looked at the ICAD report. We mapped maturity and adoption in another spreadsheet that was out on Google. We reviewed these several times with the task force and a lot of work off-line and then we developed these overarching recommendations on the report. We can go to the next slide.

This represents our overall work plan. We did add an additional meeting from when we presented this before because we needed that for reviewing the paper. And then here we are today on the 10th. So, we can go to the next slide. Now I'm going to quickly go over the high-level recommendations and just for form, Tammy is going to go over each recommendation in general fairly quickly because we want to devote the most time here today having the discussions. Hopefully, all of you have read the report. When we have the question discussion, we will leave this slide up so you can reference the particular recommendation that you might have a question about, or you want more information on. Essentially, we have 13 recommendations.

They focus on certification, the implementation guides, we do have a whole recommendation on patient-centered because that is an area that we felt was a gap in the RFI. The prior authorization road map, an adoption at scale, and an approach to how we might do that. Some regulatory coordination that we felt was required. We have a recommendation on attachments. Then we have another recommendation about a proving ground or ability to have a place to do some pilots and testing in an integrated fashion. Realizing that, as I had indicated before, the three components of electronic prior authorization may not all exist in one system, and that's kind of a unique situation for this process within a provider setting, how would they all work together?

So having the flexibility of having some type of support. Sorry, the chat keeps coming up and blocking my view. The support for testing and proving that is going to be important to ensure that this is something that can work. And then having the flexibility to have testing with maybe some leeway and guidance relative to how fire and X12 will work together is discussed in these recommendations.

Then the establishment of an advisory process, as well as health IT at scale, meaning how do we need to set this up so we can more readily adopt it. Innovation and integration and then we talked about ePA bundles and Tammy will talk about that and multi-stakeholder engagement. With that, I will turn it over to Tammy and we can go to the next slide.

Tammy Banks
Thank you, Sheryl. Thank you again for the opportunity to share the excellent work of the ePA task force. Many of these recommendations, as Sheryl said, I will be going through will be familiar to you since they are directionally the same as we discussed during our previous conversation. I am only going to focus on points that may have expanded or been added to our previous list to give us more time to answer questions.

With that, recommendation one: is focused on the provision of a complete prior auth solution within the provider's workflow. The task force recognized there can be multiple health IT systems, revenue cycle management, practice management systems, EMR, Smart App, or other vendor solutions or intermediaries that provide one or more capabilities to the PA solution contained within the provider workflow. Therefore, the recommendation is for the ONC to provide health IT systems a module or suite of ePA IT certification criteria along with the ability to certify to one or more specific capabilities that together across the participating health IT systems can engage in integrated full ePA full workflow.

These criteria should be in a stage and tiered approach to provide an initial baseline that enables IT, developers, to create road maps based on their state of readiness. The recommendation mostly focused on prior auth for procedure services and other items, like DME, however, the task force expanded the discussion to include 1.6 which recommends changing the NCPDP script transactions related to prior auth, from optional to the criteria to mandatory. To better support the ePA process for drugs under a prescription benefit.

Recommendation two: You will notice the theme that is echoed throughout these recommendations is a call for collaboration as reflected in this recommendation. ONC should work with the Da Vinci project and key healthcare stakeholders, which includes providers, developers, patients to develop appropriate health IT certification criteria. The task force provided input on the readiness for the adoption of these guides. The coverage, **[inaudible] [00:22:34]** discovery, CDR, document templates, and rule DTR and prior auth support as implementation guides in a spreadsheet you would have found on appendix B.

To convey an example is only to begin the conversation. The task force recognizes that the complete suite of Da Vinci IGs is not yet ready for implementation at scale and that there are different levels of maturity for each of the IGs since each of them addresses a different phase of the prior auth workflow and each implemented as a standalone solution. So, pieces of the IGs that are ready, available, and provide value should be identified in the certification strategy along with a timeline. However, the combined IGs must be implemented across the relevant IT systems to fully digitize the prior authorization workflow and deliver an overall solution. The task force stressed privacy and security of the data should be considered in the criteria development as well as considered by the health IT developers during the development and implementation of the solutions.

Recommendation three: The movement toward patient-centered inclusion in ePA was high on the priority list and many of these recommendations we discussed during our last presentation. The major change is direct ask for ONC to work with standard developing organizations and other key stakeholders to raise the priority and buildout standards to meet the patient use cases we discussed. To provide for patient transparency and engagement and determine if existing standards like Blue Button 2.0 API or related implementation guides should be amended to support the patient use cases. The bottom line: we recommend the ONC road map include plans with specific timelines within future ePA processes to allow patients to opt into transparency and engagement.

Recommendation four: Conveys the task force's strong position that both the provider and payor IT systems need to be included in a health IT ePA road map that should be created by HHS. Payor HIT systems need to be able to send the information for the provider HIT system to respond and vice versa, the provider HIT systems need to be able to send the appropriate information for the payor HIT to process the prior auth. Therefore, the certification strategy should include HIT systems, supporting payors, and providers, and be

based on FHIR-to-FHIR endpoint transactions or initially on the source of the information. Payors for coverage and termination and documentation requirements and providers for accessing to support the information.

Additional key points, certification criteria should be adopted in the tiered and stage approach. Providing baseline functionality as well as a road map for cutting-edge organizations. This provides directionally sound guidance to allow innovators to test and lead the development of future capabilities on the road map, reducing the need for proprietary solution development. A sign in the timeline aligns the maturity of the capabilities within the Da Vinci IGs and the speed of the industry's ability to comply will be important. The timeline should be informed by an environmental scan that assesses the readiness of the IGs and identifies the functionality that provides value to patients, providers, and payors.

Recommendation five: Adoption at scale for the road map to be successful, HHS should develop an informed and vetted iterative rollout plan. The task force recommends the plan for adoption maturity at the scale of a fully functional prior auth workflow by setting or service with no requirements rolled out until the standard has been tested in that practice setting and for that type of service. For example, imaging.

Recommendation six: Given the emergence of new standards to support ePA, HHS should ensure that regulations allow multiple standards to at least temporarily co-exist as they are tested and used by stakeholders to meet specific business needs while preserving widely used existing standards and addressing gaps. Prior enabled processes for prior authorization transactions should not require the use of translation to X12. Simplified, the HIPAA exemption to the approval process of testing emerging standards for beta testers and collaboration with CAQH core to add response times as contained in its PA operating rule. For the **[inaudible] [00:26:37]** interactions that the ePA information guides are introducing is asked in this recommendation.

Recommendation seven: Attachments. The task force focused on attachments for ePA. The main theme is moving the health care industry from a document-driven approach to an event-based and data-driven approach. The task force would like to leverage existing infrastructure and recognize the current need to exchange C-CDAs and other attachments for claims, risk adjustment, and other use cases, but inform future investment leading to data-driven information exchange. This will remove that extra step to respond to a data request by allowing the collective data to be directly sent back to the requester instead of having to put the data in a document format before sending. Therefore, a flexible approach is needed. The task force recommended keeping the **[inaudible] [00:27:27]** attachment functional requirement optional with further maturation in testing CDA attachment IG and/or FHIR documents before considering it as an ePA minimum standard. The task force recommends ONC prioritize criteria based on that path's IG that allows data, C-CDA, or FHIR documents to be provided in an FHIR construct to support an auth request in the short-term and aim for a more automated approach based on FHIR-based APIs to gather all relevant data.

Recommendation eight: ONC should develop and fund a proving ground to support the maturation of IG's supporting ePA. This includes encouraging and monitoring some new testing of the IGs, validating and improving the standards, requiring pilots and early implementers to publicly report key metrics, along with requiring an independent review of ROI and analysis to demonstrate and improve metrics related to the ePA process.

Recommendation nine: ONC should establish an advisory process to evaluate readiness and maturity of the EP IGs and make recommendations for certification enhancements, identify gaps, and encourage the development of additional capability, such as the patient center transparency. Increased collaboration and extended federal funding to accelerate movement to scale. Ensure criteria contained with the inoperability standards advisory and recommend updates to standards we addressed through the standard version advancement process. Most importantly, enable stakeholders to come together and make sure each stakeholder's capabilities and the implementation timeline match with the focus on API conformity.

Recommendation 10: Accessibility of health IT for ePA at scale. Recommends HHS explore additional incentives to support to ensure ePA processes are effectively adopted and implemented across the care continuum. Especially support smaller under-resourced providers and adopting and implementing standard ePA technology. Success will be realized only if all stakeholders have the criteria and access to technical capabilities to share accurate and complete information required to process a PA. Stakeholders need the option to choose preferred systems to initiate an ePA. The certification program should group complimentary health IT products into suites of modules that support ePA to make it an easier decision. Supporting payor overall reduction in the volume of prior auth requirements will also be necessary for widespread ePA implementation.

Recommendation 11: Innovation around ePA integration physicians do not typically perform a complete prior authorization, but delegate to handle the supplemental information request and other follow-up required. Therefore, ONC should require a health IT system to provide rule-based delegation to the back of the office staff and/or patient to complete prior authorization requests and/or respond to prior payor supplemental information requests. Additionally, tools should be made available to trigger a new renewal PA that may be submitted by an expanded group of stakeholders to enable ePA processes based on best practices. The task force envisions a third-party intermediary or patient may need to trigger DM requests in the future as one example.

Recommendation 12: We discussed this recommendation on the previous call and due to your interest, we pulled into a separate recommendation. Recommendation 12 asks HHS to encourage payors by putting levers in place to continue to move toward an episode of care complete treatment plan for bundled services including ancillary services required to complete the service for prior authorization review and decisions. The task force also encouraged further study; of the required capabilities, additional code options, or concurrent care authorizations that need to be included in the future Da Vinci CRD IGs to meet the business need.

Finally, the task force cannot underscore enough the adoption of the ePA process requires buy-in from the team. Payors, providers, developers, patients, and other key stakeholders as well as feedback from other departments, agencies, programs across HHS throughout the development of the health IT certification criteria and road map. If one stakeholder group lags the building capabilities all the stakeholders will not realize the benefit of the digitized ePA's process. Thank you for listening in. Are there any questions or recommendations you would like to review in more detail?

Sheryl Turney
Can we put up the slide with all 13 recommendations on them, please?

Aaron Miri

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Yeah, there we go. Let us put that slide and we can work here. Okay. So, first up with their hand is Arien Malec.

Arien Malec
Hey, thank you so much. There is a lot of amazing work. I want to dig into the attachments recommendation, just make sure I understand it. Are you recommending, so, when we did this on the ICAD task force, our recommendation was to proceed with attachments and build a road map to full FHIR support? And I am not sure I understand the attachments recommendation as to whether you are recommending proceeding with attachments or holding on attachments until attachments fully support an FHIR bundle as well as a CDA.

Tammy Banks
Great question. I think we are right in line with where you are going with building a road map.

Arien Malec
Got it.

Tammy Banks
But we recognize we need the flexibility to allow innovation. So, we cannot just mandate one way.

Arien Malec
Perfect.

Tammy Banks
We need to allow the innovators to be able to continue to look at what document-based exchange today can be moved to data-driven and there are systems, of course, that have to be built. So, I think we are right in line.

Arien Malec
Perfect. Again, I want to re-endorse this notion, because this all came out of the ICAD Task Force, that to get to the future that we are going to, we need a more flexible standards advancement process for administrative standards similar to the one we have been using or are working out the mechanics of using on the clinical side that we have historically gone full bore only one thing allowed at a time major mass transition and this approach of allowing more incremental testing, piloting, and use. And the ability to support multiple flavors of the same thing at the same time while it adds heterogeneity to the interoperability landscape.

I think if we see the progress of administrative standards, we've had these major cataclysmic shifts every ten years or so, as opposed to the more incremental pace. And more rapid, even though it does not seem like it sometimes, the innovation we have had on the clinical side where we make uplift every three years roughly and we have been able to move forward in ways that seemed slow on the ground, but if you look back over the past ten years, we have made tremendous progress. So, I completely endorse that and really, thank you for your work.

Tammy Banks
Thank you. Yeah. That was a strong conversation we had that we have to allow the innovators to kind of test the ground, right, and bring it back to bring the larger market share to increase the capabilities.

Arien Malec
Good deal.

Sheryl Turney
I do not see any other hands up but.

Aaron Miri
I do want to say, Sheryl. Let me just go ahead and remind the HITAC, comments are due by the 22nd of this month so we are running close to a window here. So, we need to reach a conclusion on recommendations today.

Sheryl Turney
I agree. I wanted to point out that Leslie had made a comment or question in the chat. So, I do not know if that requires some conversation.

Aaron Miri
Yeah, Leslie, do you want to speak up in public here and talk through it?

Leslie Lenert
Sure, let me just say I had four thoughts I wanted to do in here. One was on, and you can read them in the chat, but I will just say, rule-based methods for prior auth do not simulate human thought and we have artificial intelligence methods that come close to that right now based on clinical judgments of appropriateness and the future of prior auth need to focus on how AI can be brought into prior auth. Not using technology from the 90s, 80s.

Second, one of the critical issues is, are we going to bring the rules to the data or the data to the rules? And it looks like the Da Vinci architecture focuses on bringing the rules, I am sorry, bringing the data to the rule engines that the insurers control. Rather than bringing the rule sets to the EHRs to be executed there where the data are, and the patients are. I think the technology exists or is very close to existing to bring the rule sets to the EHRs. And that is a much more transparent process because there is no one hiding behind the curtain saying yes or no, thumbs up or down, give me more data. That the criteria are clear. And I think that is important for any process that is fair is for the criteria to always be transparent.

So, the last thing I would say, and you can read the comments in a more detailed fashion is, whatever architecture we wind up considering it should be a part of the **[inaudible] [00:37:02]** and we should recommend creating a QN that helps implement the prior authorization and serves as a hub for payors to receive data from the health care system and for the health care system to send data because this will accelerate the process, rather than adding millions of connections to thousands of payors.

Tammy Banks
Thank you for bringing that forward. I think we focused in our discussions that the implementation guides that are being developed are focused on the rules related to the data requirements and not the rules that a prior auth would have to follow to be approved or not. So, there is a little bit of a distinction there and I see where you are going with it. But that was not a topic that we discussed in our meetings.

Aaron Miri

Yup. That is a good point, Les, and I am glad you stated it for the record, and we also have that in your chat.

Tammy Banks
Yeah.

Aaron Miri
It will be something to follow up and this could be a conversation that goes on for a while so that coloring is really, really important. So, thank you for that.

Tammy Banks
Yeah.

Leslie Lenert
And I would like to applaud the tactical work that has been done here to move this forward. I think, in particular, in regards to the requirements for patients to have visibility in the process. **[audio cuts out] [00:39:01]**

Tammy Banks
I think we are losing.

Aaron Miri
Yeah. We are losing you, my friend.

Leslie Lenert
And that is really, **[inaudible] [00:39:11]** us and that we do need to do that. Okay.

Aaron Miri
No problem. That is no problem at all. We have got you. That is okay. All right, so next up to tell us about how technology that he wrote in the 80s and 90s is still relevant today and good is Clem McDonald, next in the queue.

Clem McDonald
Well, this strikes me as a ton of work, but it is so big that it will not get done. I would just advise dividing and conquering. Take a couple of chunks and get them done. You know, I lived through the attachment process, which I think went on for 20 plus years, and still is not done, and it was much simpler. I mean, I think you really have to, a lot of what you need to do in prior auth is get the facts. You know, get this report and that report. That is almost cooked now given what is happening in ISA, I mean, in USCDI. The reports will be available, an x-ray will be available, hopefully. So that you can pull these things pretty easily as a simpler piece. But I just worry about, you know, people have rotated off this committee, before it gets done, and then you have to start with new people.

Sheryl Turney
That is a good point, Clem. I think that is one of the reasons why the task force really focused on a road map and basically a timeline where we could implement based on maturity and creating that advisory process similar to how it can feed into the ISA process so that we have sort of what is ready for adoption,

what is near adoption, what needs more work, and that was to provide that pathway so that things could be done iteratively because we did discuss that at length.

Clem McDonald
Good. Okay, thank you.

Sheryl Turney
To try to address that. So, hopefully, it came across in the report. I know there was another comment in the chat that I did want to call out and that was from Alexis Snyder regarding work being pushed to the back office.

Aaron Miri
Oh yeah. I missed that one. Thank you very much, Sheryl. Good deal.

Sheryl Turney
Patients need to make sure that patients are engaged only as much as they want. And the way we try to frame the verbiage in the report was so that it can be the physician's decision. Some people wanted prior auth to kick off automatically. Others are physicians who want to have control over that process. So, I do not know how you make all things happen for all people, but we did talk about having the capabilities within whatever system that physician has can be customized if you will to allow that process to occur. So, if they want to handle it themselves, they can, or they can design the role within their system for someone else to handle it.

And then regarding the patient, we did make a very big point in the patient center recommendation that the patient should not be forced to be included if they do not want to be and even if they do want to be included, they get to choose how much information it is. Some patients may only want to know the status of the progress. Others may want copies of everything. We are not going to dump tons of information on people if that is not what they want, but at the end of the day, if they do want to know the status, and then of course, if their PA is denied, they are going to want to know how to appeal. So, we focused on not only the choice but what information at a minimum they should have if they do want to have entry into that process. And then also, some coordination with the advanced or the estimates for the advanced EOB. Because at the end of the day, Cynthia brought up the cost in the prior discussion and we did want to make sure that there was some collaboration or coordination on that issue as well.

Aaron Miri
Yeah. What I like about this, and I can appreciate what Clem was saying regarding the comprehensiveness and the total body of work, at least now when you mention and say prior auth, a lot of people say that sort of figuratively or loosely without really understanding the meat of what goes into prior authorization, the number of steps there. And it is a very complex issue. The intelligence of this request for information and the list that we put together here really starts giving us a road map. It is a big body of work and why it has not been solved, air quotes. It is a lot to do, Clem is exactly right. But here is a working road map that we can take chunk by chunk. I think Arien was saying that in the chat too. At least get some of this going now while we have our eyeballs on it. I think it is great.

Sheryl Turney
Exactly.

Aaron Miri

Other comments or questions here? We have a couple of minutes left and I want us to go for a vote here, but I want to make sure the HITAC members want to voice questions, ask questions, concerns, thoughts, opine, whatever may be it. Anybody else with comments or feedback? Otherwise, we can use the extra time for the panel this afternoon, but this is an important topic. I do not want to shortchange it at all. Okay. Give one more minute for any other feedback. Steven, Steve? All right. Ike! Go for it, sir.

Steven (Ike) Eichner

Thank you, sir. Do we need to do anything special about addressing things like Gina and constraints on information with an insurance provider to ensure that it is only the information necessary for reviewing the prior authorization and not for other materials and that information is not retained for other purposes?

Sheryl Turney

So, we did speak to that in the recommendation. We did talk about only collecting the information required for the decision-making. About the point about materials not being retained, we did not address that in the recommendation.

Steven (Ike) Eichner

Retain may not necessarily be the right word here but looking at subsequent use. In other words, collective for purpose, used for the purpose, retained as a matter of record, but not reutilized inappropriately.

Aaron Miri

Okay.

Sheryl Turney

Good point.

Aaron Miri

Great point. Great point. Other comments, questions? Concerns, thoughts? Commenting on springtime showing up soon hopefully? All right. Eliel, go ahead.

Eliel Oliveira

Yeah. So, based on some of the comments, we did discuss a lot about the patients **[inaudible] [00:46:01]** here and the size of how these last, you know, would become a reality and we did capture the road map and the proving ground and how to do all of this. I think when the heel is off the equity work that we are just going to start, I will say that a key aspect to consider here is the patient gets involved in any of these recommendations and a proving ground and the road map and the advisory process from the beginning, not as a side thinking process. I think the example that I will give here is how the patient set of outcomes research institute was created where no research project gets approved unless the patient was part of the design process with the researcher. I think that is one bit of advice I will provide to HITAC to consider in any aspect of this going forward: making patient-centered and health equity a center point.

Aaron Miri

Good points. Good points, Eliel. Other comments or questions?

Denise Webb

Aaron? I want to say what a great job the task force did. I participated in the ICAD task force, and it is really exciting to see that we have a path forward here with these recommendations.

Aaron Miri
I totally, totally agree.

Denise Webb
So, I thank all those who participated.

Aaron Miri
Yeah. We have a list of recommendations to vote on here in a minute on Super Mario Day of all days. I just found that out. So, it is. All right. Other comments, questions from the HITAC? This is a good discussion. All right. Well, then I think we are ready to go for a motion to adopt. The e-Prior Auth RFI Task Force Recommendations? Unless anyone has any other comments, one last time? I just want to say before we ask for official someone to nominate this. All right? All right. So, may I have a motion then to approve?

Arien Malec
I motion to approve.

Aaron Miri
All right.

Hans Buitendijk
Second. Hans.

Aaron Miri
I'm sorry, who was that?

Hans Buitendijk
Second, Hans.

Aaron Miri
Got it. All right. All those in favor please signify by saying aye.

[Chorus of ayes]

Aaron Miri
All those opposed please say nay. And any abstentions. Okey-doke, these are approved. Great, great job, team. That was not easy to pull together in a short time period, but two experts in the field leading the group, what would you expect? So, well done, very well done. All right. Denise, what's up?

Denise Webb
Yes. Thank you, Tammy and Sheryl. All right. So, next, we are going to hear an update from the Interoperability Standards Workgroup co-chairs, Dr. Lane and Arien Malec.

Interoperability Standards Workgroup Update (00:49:01)

Arien Malec

Good morning. We are here for an exciting update. Not that exciting. This is the warm-up for the main event which will be at our next HITAC meeting, but we have made a huge amount of progress between now and then. And I just wanted to give you a sense of the work that we have been doing. If we can go to the next slide. Here is what we will be doing. We will be re-reviewing our charge and what we are tasked to do for the next HITAC meeting and then I will turn it over to Steven to talk about the hearings that we have held and kind of where we are going. If we go on to the next slide.

As a reminder, we have two main events. One next month where we will be providing recommendations relative to draft USCDI v3. And we are at this point we are combining charges 1A and 1b, so we will come up with a streamlined set of recommendations for draft USCDI v3. And then we get to go do it all again in June where we make recommendations relative to the ISA. So, think about this as the USCDI is the data model for interoperability. It is the data for which interoperability is constrained and then our ISA work is the interoperability use cases and implementation guidance and making sure that we have got an advancement there. So, on to the next slide.

So, in general, we were asked to look at draft USCDI v3. Make sure that the proposal for USCDI v3 made sense, particularly that the data elements made sense, that the names, definitions were consistent. Look at some of the stuff that was on the bubble related to v3. And make sure that we have standards readiness and industry readiness for v3.

In addition, we were asked to take on two specific topics, three here, but really the first two are bundled, and then based on the discussion that we had at the HITAC for the last USCDI review, we took on additional hearings for one other topic. The two topics that we were asked specifically to review were the Gender Harmony recommendations. So, Gender Harmony is an HL7 task force looking at gender and sexual identity. And want to make sure that we have clear alignment to those recommendations as well as related recommendations from NIH and others, and in particular we were asked to look at sex assigned at birth and gender identity. We were also asked to look at the US@ spec project, Project US with a little at sign for address, and review those recommendations relative to USCDI v3 and we additionally took on a set of hearings to look at disability status, functional status, cognitive status because there had been a set of comments related to those statuses in the last HITAC where USCDI was reviewed. That was where our specific charge relative to USCDI. If you can go onto the next slide.

We will not drain this slide, but we have a highly engaged task force. We benefit from the range of backgrounds and perspectives that the task force or the workgroup provides, and we have had a substantial set of discussions related to the hearings, as well as the material for USCDI v3. And with that, I will turn it over to my colleague, Steven.

Steven Lane

Thank you, Arien, and I want to thank our task force, workgroup members. We were a task force last year; we are a workgroup this year. People have been incredibly engaged and brought a lot of insight to this work. As you heard from Arien, we had specific requests from ONC to dig into some demographic data as well as issues related to health status, data class.

So, we have had specific and focused presentations or hearings, if you will, from the leads of the Gender Harmony project, the Project US@, as well as several subject matter experts in the area of the data elements that have been identified within the health status data class. So, this has been most helpful in giving us a lot of information. There have been extensive discussions that have led from these presentations about patient demographics in particular the question of whether gender-related elements and addresses should be included with indeed a focus on developing or identifying a standard methodology for identifying individuals who are experiencing homelessness as this is seen as a key part of addressing health equity issues which we will be spending a lot of time on today.

Under the health status and functioning, several interesting questions have arisen. One was whether disability status really should be identified as a component within demographics or whether that is more appropriately part of health status. It ends up, from a USCDI perspective, it almost does not matter which data class a specific data element sits under because we are still talking about the data itself that will be required for interoperability. But these are important questions and there are people with very strong feelings about them, so we are addressing those.

There is a lot of discussion about whether structured assessments should be brought together within the health status data class as opposed to their current positioning within multiple data classes around the USCDI. And then a key question and this also came up in our task force last year, as to whether there is added value of identifying specific assessment instruments that are coded within **[inaudible] [00:56:02]** as an example, they could be used to document specific aspects of a patient's health status, be it their functional status, mental function, et cetera. I think these are key architectural questions about USCDI that we are also contemplating. Let us go on to the next slide.

We have used a process that is now familiar to many of you who worked on task forces and workgroups. We developed Google Docs, one of which has been used to capture task force member recommendations about changes and clarifications to the data classes and elements that were proposed in draft v3 as well as level 2 data elements that could be added to the final version 3. As usual, there is a lot of interest in data elements that are down at the comment or the level 1 level within the system. And we are capturing those, and we will come back and be talking about those later in the second part of our workgroup work when we focus on the ISA.

We have had a lot of discussion about the readiness of each of the new proposed data elements for nationwide exchange as well as a balance and benefits and burdens of making such additions to the USCDI which is the data test that all certified IT will eventually be required to exchange, as opposed to leaving them as additional elements that could be exchanged but will not be required. We had several specific requests from CMS to add data elements to related encounters, facilities, medications to support their work and quality measurements and reporting and I think we are struggling a bit to clarify which of these belong in the core USCDI data set and which will belong in the new USCDI+ model that is being developed but is specifically out of scope for our workgroup.

So, on to the next slide, we have several meetings scheduled over the rest of this month and next to prepare to bring specific recommendations back to the HITAC next month. I do not think that we are going to get through full adjudication of all of the recommendations that have come forward, so we are trying to prioritize those. There is a particular interest in addition to finalizing the recommendations around the items we discussed already and there is interest in exploring the addition of data elements that could be used to

capture patient-generated health data and exploring the utility of adding author as a data element under provenance as a way to more clearly identify data that is generated by the patients. We will see if we have time to cover that. We have a lot of work to do, and we will be back next month with a set of recommendations would welcome any questions from the HITAC about the process so far.

Denise Webb
Thank you, Arien and Steven. I am not seeing any hands up. Any questions or comments from the committee?

Cynthia Fisher
Hi, this is Cynthia Fisher. I cannot find my hands up, but I just wanted to connect with you all on the patient feedback where when the EHR is incorrect, where there may be something reported like an incorrect test result or an incorrect note to the file. So, I would like to know if there is more readily accessible for patients to change this record because physicians and the hospitals tell us that they cannot change the record even when it is wrong, but that they can add a comment into the physician notes. But I think it is more likely that we have patients complain that they have tried over months and months and years to try to get their EHR corrected rather than have it be permanently wrong.

Arien Malec
Yeah, thank you for that.

Steven Lane
I am happy to respond to that. You know, this really falls under HIPAA. And the ability for patients to request amendments or addenda to their record. It does not fall under the USCDI at this point, which about is the data elements and classes which are used for exchange. But it is an important point, Cynthia, and one that should be addressed. I do not know that the ISA really even is the place. I have not heard about any standards work being done to capture patient amendments or addenda. If others do perhaps it's something we could take up as part of our ISA task. I am curious what your thoughts are, Arien.

Arien Malec
Yeah, so first of all, I just strongly endorse the notion that patient right to correction is a HIPAA right and is a basic assumption of the U.S. healthcare system even if it is not honored in practice. Secondly, while the specifics of patient amendments are not in scope, definitely patient-generated health data are in scope. And so, the patient-generated health data includes patient self-observation, patient self-assessments, as well as patient notes. And so, there is definitely, definitely work there. And then Steve Posnack and Grace both point out in parallel that there is HL7 work going on using FHIR to support a patient correction process.

Cynthia Fisher
Yeah so, I mean, it goes into this quagmire black hole and the patient is mistreated and mistreated and even say, even denied surgery if something was incorrectly put in about their health ability for that surgery. So, we have had people and physicians just throw up their hands. So, I think somehow as we address it, wherever we address it, it needs to be easy for both at the point of care to make that correction and take out the permanence of such erroneous record reporting and even coding.

Arien Malec

And I think we all agree. It might be helpful for the coalition that you represent to be engaged with the HL7 process on the FHIR patient correction standard because one of the easiest ways to have a standard way of doing this is to test out that there are standards that are in use and trialed and then it is a lot easier for ONC, for example, to require those standards about certification.

Cynthia Fisher
Well, maybe off-line, Arien, you can help us figure out how we can make that expeditious and efficient because, you know, otherwise patients' health can be harmed.

Arien Malec
No doubt. Absolutely.

Cynthia Fisher
Without this addressed.

Arien Malec
Been there and felt it. Yup, thank you.

Denise Webb
And I would just comment that you had said this is really under the purview of HIPAA, but as it has been mentioned, there has to be a standard around for interoperability purposes such that a correction to a patient's record follows the data. So that when information is exchanged that wrong data that was corrected is not perpetuated through the exchange of health information.

Steven (Ike) Eichner
This is Steve Eichner. I guess I would add into that one that the correction or update should take the place of the old data at least in terms of priority. I appreciate the need to retain provenance for something that may have been entered incorrectly, historically just from a documentation standpoint, but the correct information must be presented down the line first, not the incorrect information presented first, as in oh, yeah, we corrected it later somewhere buried a little farther down. Or if you look at the detailed record the current and correct information should be presented first.

Denise Webb
Yeah. It has to be tagged or something, Ike, the incorrect information tagged so it does not get shared and perpetuated.

Arien Malec
And there is some provenance information that is in USCDI. We certainly contemplated looking at the provenance of the data elements. I will also post the OCR guidance on the right to correction to the chat.

Denise Webb
All right. Any other comments?

Steven (Ike) Eichner
I can just.

Cynthia Fisher

I think the other thing, this is Cynthia, sorry. The other thing on this is that it also affects patients' billing if they have been, say, erroneously diagnosed or, say, in a mammogram, for instance, and then they become a diagnostic versus an annual screening. Then the charges are substantially higher, and they forever go into this diagnostic and get up coded too. So, patients do not know how it even affects them negatively financially too, because of how the EHR and the financial records are interrelated. So, I do think we must find a way that these remedies can be done on point at the time they are discovered and with a sign-off by both the patient and the physician that knows that it is erroneous.

Denise Webb
Thank you, Cynthia. Steven, you have your hand up.

Steven Lane
Yeah, I think again acknowledging that this is outside of the scope of the USCDI work of our workgroup, but I think we do have an opportunity to bring this up when we focus on the ISA coming up in another month or so and see whether there is an opportunity to include the work that is being done on FHIR and call that out in ISA. And then I also think that as we rekindle the HITAC report workgroup for this coming year, we could consider adding that into that report to stick a pin in that to make sure that it is on the agenda for ONC. So, thank you, Cynthia.

Denise Webb
Thank you, Steven. All right. Any other hands? I don't see any.

Cynthia Fisher
I have one more hand. And I do not know if this falls into patients getting access to their records, but a lot of the systems like Epic now have sign-ins. If someone signs into a hospital or appointment, it is on a little pad, and they are given an electronic pen. But they are not printed out or they do not know what they are signing because they do not read anything. They are just told, okay, sign in. The patient does not get on this distribution the documentation that the hospital has upfront, which has them sign away the release of all of their information and their billing information and their responsibilities to pay.

And I find that also those hospital forms we find for our patients are coming to us to say that the hospitals are preventing them from paying cash or direct paying because there is no electronic format that gives them the option for self-pay. They still sign; even if they pay the cash upfront in direct pay, they are signing into the terms that insurance could be billed or that they are responsible outside of any other charges, et cetera, et cetera. So, they are duplicating even if it is a cash payment and there is no alternative. So, it's not accurate for the patients that directly or self-pay. And yet they have no documentation to support that.

So, many patients have come to us being double charged. So, both their insurance is billed, and they were self-pay. So, I just think that this is important in the documentation that goes to the patients as well as, and perhaps, again, you all are the experts. Where does that go that the patient have the provenance of the terms and conditions of their contractual relationship with the provider?

Arien Malec
And again, I think there are cases where there is waste, fraud, and abuse, or there is a violation of existing rights under HIPAA. And OCR generally is the agency that should be, who has the mandate to do that level of investigation. There is a technical point if the legal agreements that a patient has signed are part of the

designated record set and I do not think any of us have the competency to say whether a legal agreement that a patient signed is formally part of the DRS. If it is, then it is absolutely subject to the right to access. As Aaron points out, the implementation of sort of the second stage of information blocking makes the full record including, well, the full DRS has always been available to patients under to the right to access but makes the full record electronically available. Whether that is honored in practice, as I said, is primarily a matter rather than for ONC but OCR because it is the agency that has the investigation and remedy powers.

Denise Webb
All right. We have about three minutes and if everybody could raise their hand, please. Okay. Ike, you are next.

Steven (Ike) Eichner
And I guess one of the other impacts of that would be getting back data from the insurance company where it was a self-pay under those components as well because the data is supporting the claim that would be submitted and if it is self-pay, the supporting data also should not have been supplied to insurance. So, it is a complicated situation.

Denise Webb
Thank you, Ike. Any other final comments? And if not, we are going to be going to a break next. No? All right. Dr. Lane and Arien, thank you so much for your update and the great discussion.

Aaron Miri
Great job, guys.

Denise Webb
So, we are going to go into a break, and I just want to remind everybody we have frequent breaks. There is no scheduled lunch, even though we are going all day so do not forget to grab some lunch on one of these breaks. And so, we will take a break and we will return to begin the Health Equity by Design Hearing at 11:30 a.m. ET.

Aaron Miri
Perfect. Thank you.

[Break]

Health Equity by Design Hearing (01:12:00)

Mike Berry
And hello, everyone. Welcome back from the short break. We are resuming the HITAC meeting and kicking off the Health by Equity Design Hearing. And over to Aaron to get us started.

Aaron Miri
Yeah. Welcome back, everybody. Hopefully, you got a quick bite to eat or a second breakfast, as Dr. Lane was saying in our chat window there to all of us. But here now is the exciting part of the afternoon to talk about something, again, is very near and dear to my heart, but it should be affecting, and we should all be thinking about how to positively affect which is topic of health equity. With that let me introduce our National Coordinator, Dr. Micky Tripathi. Micky?

Health Equity by Design Hearing Opening Remarks (01:12:40)

Micky Tripathi

Great. Thanks, Aaron, and thanks, Denise. I am really, really delighted to be here and just want to say, you know, we at ONC and I personally am thrilled to kick off today's hearing on Health Equity by Design. One thing that I just want to layout upfront: why do we call it health equity by design? We have been working on this concept and saying this since I joined the administration, and from our perspective, it is sort of a basic simple principle that health equity should be a core design principle in health IT and health IT implementation. And in everything we do, we think about safety by design, security by design, privacy by design. We believe that health equity has that degree of importance, fundamental importance, and we should be thinking about it in that way.

And I will just take a bit of a sidetrack for a personal story here. My first introduction kind of to the importance of this was a few years ago when I was running a non-profit organization in Massachusetts and we, to support the Medicaid program, in Massachusetts, we launched a statewide event notification service to notify providers all around the state of encounters that their patients may have had in other settings to approve care management, care coordination. And one of the things that happened was we had a patient matching algorithm we had been using for years for a variety of things in our data warehouse that we were using to match up the encounters from the different organizations and to determine where to route the information.

And one of the things that we discovered after launching it, and this patient matching algorithm had gone over several reviews with technical partners from the healthcare systems and all that, and as I said it had been in place for years, one of the things that we were alerted to about a month or a month and a half after we had gone live from the safety net hospital in Boston was that our patient matching algorithm was placing too much emphasis on home address. Meaning that there were a large fraction of their patients who had housing insecurity and their home address was very fluid. And our patient matching algorithm was essentially biased against matching up legitimate encounters. It was, basically, a high rate of false negatives for those patients and therefore, those patients were not getting the benefit of the coordination that could happen from being able to identify the encounters across the system.

That was a real lesson to us on kind of the insidious effects on health equity that a lack of consideration from the beginning of where there might be health equity implications, either in design or implementation, can have on the system. We took it to heart from that experience and I am carrying it forward now. But we need your help. We need everyone's help in thinking this through. As I said, that is just one example. I think it is all over the place. And we have gotten a concept that we continue to flesh out and continue to work on, but we need everyone's help for us to figure out how do we operationalize this.

That is why I am excited about this hearing today because it is the opportunity for us to learn, us meaning ONC, HITAC, me personally, from experts from stakeholders who are on the ground doing this stuff and thinking hard about it. And we've kind of established the goal and now we want to understand what are the lessons learned and how do we carry this forward in a real operational way that will have meaning in people's lives. So, we have great speakers that we are excited about, and they will help us dissect the issue. We have kind of broken it down a little bit into issues related to data and exchange which is basically how do you get the right data to identify inequities and act appropriately. So, the first step is how do you get the right data. And then use, what can we do to mitigate inequities in care settings and further upstream

before they get magnified into desperate health outcomes. So, what are the appropriate uses of data and the effective uses of that type of data to address health equity issues?

Certainly, algorithms are just one aspect of use, but it is an increasingly important one and we at ONC certainly note the large role and increasingly large role of electronic health records play here in serving up a data that is increasingly used as the data source for the training of algorithms and another similar type of tools. Of offering the tools for local creation of algorithms and also EHR being the vehicles for inserting algorithmic results into clinical decision making. So, EHRs play a critical role here that I think we are paying a lot of attention to.

We are looking hard at that area and then certainly in our role as National Coordinator we are working with our federal partners on identifying and aligning approaches to ensure that all Americans benefit from the tremendous value that algorithms, AI, and ML tools can provide to healthcare. So, we are looking forward to this and I want to thank the HITAC and thank Aaron and Denise for your leadership on this. I want to thank the HITAC and most important I want to thank all of our speakers for the time and effort that you have spent on coming here today. And we look forward to the opportunity to work with all of your hand in hand to make sure that the technology is always part of the solution and not part of the problem. Thank you again and let me turn it back over to, I do not know if I am turning it over to Aaron or someone else.

Aaron Miri
Denise.

Micky Tripathi
Denise. All right, great. Thank you, Denise.

Framing of the Problem (01:18:33)

Denise Webb
All right. Thank you, Micky, for your remarks. All right. We are going to start with the first topic: the framing of the problem. We will have two speakers and they will each have ten minutes to present their testimony. Our two speakers are Medell Briggs-Malonson, she is the Chief of Health Equity, Diversity, and Inclusion at UCLA Health, and is a member of our committee. And then we will have Eboné Carrington, and she is the Managing Director of Manatt Health. So, I will first turn this over to Medell.

Medell Briggs-Malonson
Thank you so much, Denise, and it is an absolute pleasure and honor to be able to kick off our Health Equity by Design Hearing. The COVID-19 pandemic amplified the visualization of longstanding both health and social inequities that have existed in this country for generations. And so, for those of us who have committed our entire professional careers and even personal lives to advancing equity and justice, we know that this is a pivotal moment in our country to make sure that we take the awareness of health inequities and the acknowledgment and now start moving towards the action. So that is why this hearing is so incredibly important and I thank both HITAC and ONC for making sure this is a center point. So, I am just going to start with a framing of the problem as well as recommendations. As Denise, mentioned I am the Chief of Health Equity, Diversity and Inclusion, I'm a practicing emergency physician to this day and also an Associate Professor at the emergency medicine. Next slide.

And one of the things I always like to do when we start talking about health equity is making sure we level set, that we are all using the same definition of these terms. If not, we cannot achieve the outcomes we are committed to achieving. Next slide. So, there are many illustrations demonstrating health equity, but I tend to like this illustration the best from the Robert Wood Johnson Foundation. Because it clearly shows where equality differs from equity. So, in the first half of the illustration, you see four individuals all with very unique characteristics, but they are all given the same exact bicycle in order to ride on their journey. Now even looking at this illustration you know that some will be able to go a long distance, and some will not be able to go far, if at all. And so, this is a demonstration of equality where there is an assumption that all individuals and/or all populations will benefit from the same resources, initiatives, or programs.

Now, how does that differ from equity? Well, equity in the bottom illustration shows that now all four individuals with their unique characteristics have a bicycle that fits them the best. And now they are all able to go on the journey for as long as they can. So, this is a demonstration of equity and that is what we are focused on because we have tried to achieve equality for a while, but what we now have realized that it is equity which is the main principle that we need to uphold. So, health equity means that everyone has a fair and just opportunity to attain the highest level of health. But in order to attain this highest level of health, we have to think about all of the other factors that actually play into one having the best health outcomes and overall wellbeing. Next slide.

Now I know that this committee is very well versed on overall social structural determinants of health, and I tend to like to call them the social structural drivers of health. And the reason why is because the term driver is active. And we know all of these various factors can either propel someone's overall health and wellbeing or it can be a detriment to their overall health and wellbeing. And so, there are seven different drivers here and I will not go into all of them, but they are all interconnected in more ways than one. Everything from economics stability, playing a role in direct education, thinking about our neighborhood and built environment and environmental justice, food security, community and social context with racism and discrimination being a very important principle to address, healthcare access and quality of care, and yes, the newest social structural driver, technology. We all know that we live in a very high-tech, high digital world, and also healthcare, as we all know it here on this committee, is very much connected to overall health outcomes.

So, when we think about access to devices and the types of internets of our patient populations in our communities, when we think about both tech and digital literacy and then the various forms of data exchange and interoperability, we have to optimize these factors in addition to all of the other structural drivers to attain health equity. Next slide.

So how do we do this? Now before we get into some recommendations and thoughts about data architecture, I always like to highlight a critical error that I tend to see in numerous organizations, agencies, and when speaking about health equity, and this critical error is the racialization of social-economic status. Now, because you identify as a racial-ethnic minority, does not mean that you are of lower social-economic status. And if you are of lower socioeconomic status, that does not mean that you are a racial or ethnic minority. However, there is an overlap there. Because we know throughout our country's history, the level of systemic racism, as well as systemic poverty and classism, has caused in particular people of color to have disproportionately higher rates of being of lower socioeconomic status, but that is not the common rule. So, therefore, race is not a proxy for social-economic status and social-economic status is not a proxy for race.

In addition, how do we translate this to overall health? Well, we all know that race is a social construct with no biological basis whatsoever. That is now proven in medical evidence, especially through the human genome project. But when we think about how we have some of these adverse outcomes in terms of health, race is not a risk factor for an adverse health outcome but is an individual's risk of being subjected to the racism that causes them to have an adverse health outcome. So, systemic racism, not race, is the root of racial-ethnic health and wealth inequities and that is an important principle that we have to keep in mind as we are advancing toward greater equity and justice. Next slide.

So, how do we think and assess for patient-level inequities? This is a pyramid that I love to show which shows the progression of what we need to do to acquire the data frameworks and the analyses to impact individuals' health. With a very portion of the bottom demographics and I highlight patient-reported demographics. Why is this so important? In many of our health care systems throughout the country, our patient demographic data is recorded and collected not by the patient. And that leads to a high percentage of missingness in our data as well as erroneous assumptions on how a patient identifies. And if we do not have accurate data within our systems, we cannot identify inequities and fix those inequities. So, race, ethnicity, sexual orientation, gender identity, language, and ability status are all very important pieces that we have been working on over several years.

The next portion of the pyramid, looks at the social structure drivers of health. Yes, the seven domains that were previously mentioned, but also many of our health behavior domains as well. And then the next level, the vulnerability indices: social vulnerability index score, area deprivation index score, healthy places index score which is here in California. Why is this important? Because we have to now start taking a look at our communities and the resiliency and what is there present for us to address health equity. And last but not least the prediction tools are at the top of the pyramid. Thinking about the risk stratification processes to mitigate poor utilization of healthcare outcomes as well as overall health care outcomes and we will talk about the important ideas that we have to consider when we are using these prediction tools. This pyramid goes directly into how we cannot only assess but directly address unmet medical and social needs in the areas of care navigation, enhanced medical care, and monitoring social services, as well as public health offerings. Next slide.

So then how do we transition to also making sure that we are developing the frameworks necessary to address population-level inequities? The same pyramid, will not go through it, but now we are looking at five new domains. Looking at the clinical care we provide, the overall clinical outcomes, quality, utilization, and, yes, patient experience. And when we layer on all of the various demographic features including payor status, socioeconomic status, we can disaggregate the data down to some of the root causes but what is very important is for us to have the ability to assess for intersectionality. What does that mean? We are all made up of numerous different identities and another critical error that I see, I will call this critical error number two, is that when we are assessing our population health level data for any form of inequity, we tend to stop at race. We stop at gender identity. Without really going deeper in understanding is it race, gender identity? Is it community, is it language? Let us go and find the true root causes for some of the adverse outcomes that we are seeing because when we go deeper into the data, we can then identify the smaller patient population that is at most vulnerable for high-risk outcomes and then develop those targeted interventions.

So, therefore, high priority system needs are standard analytics and business intelligence frameworks as well as key insights. Next slide. I am going to go quickly because I received a warning. Looking at equity

focus innovation is key. Recognizing and eliminating bias, there is a large amount of scientific racism that still exists in medicine today. A perfect example is the use of the **[inaudible] [01:29:22]** filtration rate, which says that those who identify as black or African American have a different value than those that are not Black or African American. We have to identify that and eliminate those from any frameworks or algorithms that we are building upon or else they will perpetuate racism discrimination and bias. In addition, we will have to continue to strike for inclusive excellence and build systems that incorporate the voices and the needs of all of the populations that we are serving. And then designing new programs and incorporating and impacting all of the numerous drivers of health. And then last but not least, we have to have the data to make sure we are doing performance improvement and then identify the targeted interventionist to start moving the needle. Next slide.

In conclusion, what are some of the different recommendations? Number one. We have to continue to advance standardized frameworks to provide blueprints for the healthcare institutions and agencies throughout the country so we can build standardized data analytic and business intelligence frameworks to identify and mitigate inequities in health and technology. And then really amplify and lift these innovative systems that are bringing in and intertwining multiple social structure drivers of health.

And then when we think of inclusive design and we think about how we develop this while making sure our patients and our communities are at the center of this work, we have to aim for language and ability inclusivity and justice. We have to build this in a cross-cultural design, and we have to think about things from a human-centered impact. Not patient, human, because our patients are only with us for a short period of time. They are humans, they are community members, and we have to think about their overall needs. And then looking at this from a population health management standpoint.

Then last but definitely one of the most important aspects is accountability. It is time to elevate equity to the level of quality in patient safety and in fact, over 20 years ago the Institute of Medicine said that an incredibly important fundamental item of overall quality of care is equitable care. This was stated over 20 years ago, and we have not obtained that. So, therefore, it is time to continue to push forward accountability policies and structures to enforce both equitable and provisional health care services and outcomes. So, thank you. Next slide. Thank you for allowing me this time to start setting up some of the high-level general frameworks and now I want to turn it over to my colleague, Eboné Carrington, to give clear case examples and about the urgency of this work.

Eboné Carrington

Thank you, Dr. Briggs-Malonson. I first would like to thank Micky Tripathi and the entire staff overseeing the HITAC members and the organizers of this event and the public for participating in this most important conversation. You just received what I would call a master class in the landscape of health equity and I hope to amplify that message with practical and concrete examples from the field. I also would just like to give credit and acknowledge ONC and NHHS for inviting subject matter experts into this discussion to provide boots-on-the-ground experience and really take the theory from this meeting and move it forward into practice. Next slide, please.

Multiple factors conspire to prevent providers from leveraging data and technology that affects health equity. This includes the MAPs process. There are so many things happening presently that I would just like to highlight because we would like to start from the right base and ground zero. So, within the MAP partnership, there is continued support for several DOH screening measures and we would like to start the

presentation and end the presentation with acceleration and adoption of those measures and really with an appreciation for the rapid cycles of performance, improvement, and change that may be different for an IT perspective or from a legislative perspective. But we need to accelerate the pace of implementation of these standards. I would also just like to say that from a health equity perspective, and we will get into this just a bit different later in the presentation, COVID-19 laid bare so many structural and systemic racist issues that require us to act very quickly. Next slide.

When we look at the deep-rooted health inequities that were presented during COVID-19 and we saw, to Dr. Briggs-Malonson's point, that race, where you live, where you go to school, where you play, they all have extreme impacts on your ability to optimize your health outcomes. And what we saw in communities of color was that these health disparities were more prevalent. So, the development of data elements and measurement approach is necessary for us to be able to quantify and to address and remediate certain of those structural drivers and those circumstances. Rapid reliance on imperfect data is going to be something that we will have to be more comfortable with as past dependency has been weight-limiting in wielding these innovation cycles. We need to talk more with beneficiaries. We need to ensure that as we are trying to offset or address social drivers, we talk with the people who are experiencing the obstacles in their lives and the challenges that stop them from living and optimizing their best health. Next slide.

There is wide evidence that social drivers drive about 80% of health outcomes and they impact healthcare expenditures disproportionately. Communities of color have been impacted and there are no drivers of health measures in any of the federal quality and payment programs at present. And I want to rest there because that is where the evidence rests on why we need to amplify and accelerate this message. Dr. Briggs-Malonson showed us a figure and talked about all of the ways that data can inform health equity and I am just going to zoom in on two of those. The specific social drivers of health in the seven domains it is required that we document those so that we can understand and crosscut the data to be able to help and provide wrap-around services and programs to patients who experience complicated issues.

And I will just unpack for a moment a patient with complicated diabetes or hypertension requires a difficult decision point with limited income. Do they take their medication? Do they use their paid time off if they have any? Do they go into debt to ensure they are care compliant? These are things we cannot measure at present because the nuances of the total patient are not captured in the medical record. And so, we are looking to have more adherence to documentation requirements around the utilization of the Z and G codes there are developments of such codes under the Gravity Project and what we are looking for is federal requirements in the lens that compel providers to document this in a standardized way so we can have comparative metrics. We can dig deeper into some of the issues that affect these patients with complicated presentations. And we can put in incentive payments so that the individuals and the providers that care disproportionately for communities of color are not further financially compromised having to add data components and elements.

So, what I will say is food insecurity, housing instability, transportation, utility, and interpersonal safety are not routinely documented in medical records in ways we can prepare to be able to remediate and program development to be able to see improvements outside of small demonstration projects and to be able to advocate to our local elected officials and up to the federal government around programs and services that are socially driven that can help optimize patient outcomes. Next slide.

So, we recognize the disproportionate impact of drivers of health on Medicaid beneficiaries. And the imperative to enable measure alignment across the EMS program is imperative. Members of the Medicaid Adult and Child Core Measures Workgroup have submitted analogous DOH screening measures in January and we want to draw on some of those learnings. So, what we have seen, as Micky pointed to, in Massachusetts and North Carolina and many other states is the adoption of instead of payments for wrap-around services, which is a way to fund under-resourced providers, including community-based organizations, to address these patient drivers and I just want to rest for a moment on what they look like in the field. We spoke about race not being exactly correlated with social status and I want to highlight Serena Williams in this case.

From a maternal mortality perspective, being born a woman of color at least amplifies your ability to die in childbirth by five and so I want to offer that being a woman of color in this country puts you at higher risk for dying during childbirth that has nothing to do with your socioeconomic status, that has nothing to do with your behaviors or your neighborhood. It truly is an artifact of bias. And so, we have got to talk about that, and we have to make sure we have programs and services that incent providers to address and train on implicit bias, to invest in, what I would call, exploratory listening with their patients to build trust so we can calculate social drivers and determinants to be able to put programs and support in place. So that is one way we see social drivers present in the health care setting.

Another is during the COVID pandemic where we saw a disproportionate impact of communities of color both in terms of hospitalizations and rates of COVID infection but also the disproportionate negative uptake in certain communities. And so, that speaks to a lack of trust in the healthcare system in this country. And it speaks to the need to tailor solutions to people, particularly the understanding complex presentation of themselves and their communities and that is why we must document, quantify, and measure this data in a very different way. And that is why we are compelling this committee to review the managed care requirements and rules so that we can contract differently. Yet, we have no standardized measures, so we continue to struggle. And for the past two years, this workgroup has identified opportunities, yet we remain without significant action so all we are looking to do today is to encourage and spawn more conversation around the subject.

And so, I am just going to take you to a specific case study occurring now in New York, if we go to the next slide, where we will speak about what a lack of measurement looks like in terms of program development. So, New York state has put forward a concept paper on one of the ways that Medicaid authority can be used to address social drivers and that is through demonstration projects. And within this current concept paper from New York state, the goal has been to build a more resilient and flexible care delivery system that reduces health disparities and promotes equity. No more appropriate topic than we are discussing here. And what I would like to highlight is that the utilization of HEROs, or Health Equity Regional Organizations, is the way which the New York State Medicaid program feels they will be able to drive forward programs around social drivers. Yet we have no measurement.

So, at this point consultatively we are engaged to try to create demonstration baselines to be able to put forward, I would probably call it, interoperable systems that can help us track referrals, close the loop, and look at what that looks like from a patient outcome perspective in terms of the change to their behavior. All of this is being manufactured and jerry-rigged with systems that have very limited resources, yet they are the ones caring for these patients. And so, what we would like to do is talk about financing equity, to make sure that the safety net hospitals are part of this conversation and brought to the table, and that there is

participatory beneficiary participation in conversations in program support around social drivers and the interoperability **[inaudible] [01:41:39]**. Next slide.

So, I would like to make some concrete recommendations. We are currently in New York trying to work toward interoperability and it is so necessary, so I have to just say we recommend that CMS guide the Medicaid IT Enhanced Fund to support the driver of technology investments. We specifically know that from an equity perspective there may be some grant opportunities for systems and providers that do care for low-income individuals as their ability to make changes to their medical records and their providers are compromised. We make a second recommendation that CMS partner with ONC directly to align their standardization efforts and to standardize the use of these data requirements and demographic data through shared governance and the re-enforcement of contracting requirements and data standards. We also recommend that ONC develop and promote the use of standardized practices for documenting drivers of health and indicators within the claims data so that we can begin to compare or measure data sets.

And then the next slide is really in conclusion, what we recommend and what we hope is that ONC and CMS work together on policies in this space that can model reflexive flexible implementation that incorporates the voice of the beneficiary that contemplates the challenges of the safety net provider and system and that brings in the community-based organizations that do have the ability to make end roads with patients and their behavior patterns ultimately that will drive down the cost of care.

So, there is an immediate opportunity to move forward on these first-ever drivers of health measures by specifically publishing the MAP recommended Medicare measures as proposed in the **[inaudible] [01:43:25]** and the federal register and to ensure we have progress on advancing these measures both with the Medicaid population and with **[inaudible] [0:1:43:34]** so I will stop there. I know that we have said a lot and I wanted to allow for time for questions, so I thank you in advance for your time and attention and again, for inviting us into this space.

Discussion (01:43:47)

Denise Webb
Thank you, Medell and Eboné. If we have any questions or comments from the committee, we have just a few minutes before we have to start the next topic. Any comments or questions? If you would raise your hand. Everybody is absorbing what they heard.

Aaron Miri
It was excellent content. My goodness.

Denise Webb
Yes. I especially appreciated the clarification on the definition of equity, health equity. It made me think of when they designed the artificial heart, and they didn't have any women on the design team. And of course, the heart that resulted out of that design did not fit in the body of women. Kind of like the bicycle example.

Medell Briggs-Malonson
Exactly. We have to be inclusive.

Denise Webb

Yes. It goes all the way to the design of our devices used in the medical field, so. Yes, Ike, you have your hand up.

Steven (Ike) Eichner
Thank you. I think another aspect of community, concerning health equity is looking at communities of people with particular conditions, especially as you look at rarer conditions, and figuring out how do we work in that space to help provide equity in that environment becomes a challenge. It may take a provider the same amount of time to review an article that 20% of their patient has as a single patient has and how do we leverage technology, leverage data, leverage non-profit organizations to improve connectivity across the provider network to get patients to caregivers that can best meet their needs and how can we leverage tools like telemedicine in our state to provide that access.

Medell Briggs-Malonson
So, Ike, if I may and I was going to respond to you in the chat as well. You are absolutely correct. Individuals that are living with rare medical conditions experience several different challenges than others, that may actually be living with other medical conditions that are more prevalent, do not. And I think that technology by far can help to leverage not only the connectivity, especially to the experts that may understand that rare condition but also the overall community context around them and all of the various aspects that they need to be as healthy as possible. And so, when we think about health equity, so often we focus on demographic features to think about health equity which is incredibly important because where we see the largest variations in both care and outcomes.

But as you mentioned, even thinking about people living with rare conditions are people that have various I will say various diversity and abilities, we have to make sure that the frameworks that we develop are taking into consideration them as well. And so, that goes back to centering inclusive excellence and inclusivity by design as well. So that if we can build frameworks and technology systems that benefit the masses, we can also sometimes take those, tweak it a bit, especially for more of our populations that are oftentimes unseen and unheard and unaccounted for when we think about technology as a whole. So, that is a really excellent point and that is definitely a critical aspect of achieving overall health equity for our country as well.

Steven (Ike) Eichner
Thank you for that. And I guess the other add-on I would mention is not necessarily looking at rare conditions, it is we are thinking of problem-solving against what might be perceived as more, if you will, traditional equity issues, thinking about things like transportation. I do think it is important that we take a holistic view of that so that as we look at improving transportation networks to provide access to care, we are also ensuring that it is accessible transportation for care and we are not having to do two or three different passes so as we are looking at leveraging things like Uber or Lyft as medical transports to support access to care, we are not leaving those folks that can't access a typical vehicle behind as well.

Denise Webb
Good point, Ike. Well, we are now at the conclusion of our first topic discussion. And I now need to turn it over to Aaron for our next topic.

Use of Data: Artificial Intelligence and Machine Learning, Systems Integration and Interoperability (01:48:43)

Aaron Miri

Absolutely. The next topic is a fun one and one might think when you think about artificial intelligence, machine learning, and systems integration, that is a lot of words, you are thinking about Hal 9000 from Arthur C Clark, you know, 2001 and 2010 and, in fact, it is more complicated than that. It is data, it is machine learning, and it is all sorts of things but at the heart of it all is inclusiveness. So, to talk to us today is Dr. Kathleen Blake with the American Medical Association, Dr. Irene Dankwa-Mullan from IBM, Dr. Ziad Obermeyer from the University of California Berkeley, Dr. Nicol Turner Lee from Brookings Institution, and Terri Willits from Anthem. And so, going forward, I am going to go and start with Kathleen Blake, please. Dr. Blake.

Kathleen Blake

Great. Thank you so much and I have to thank the prior speakers because already I am experiencing a sense of optimism and certainly the commitment on the part of ONC to progress in this area. I apologize first of all the title of my slide is the one for this program today and it's long. My focus will be on Ethics, Evidence, and Equity. Next slide, please.

I think this comes as no surprise to many of you. It is that patient information and therefore, data, the topic of this session is everywhere. And it is what data we have, how we use it, and what the outcomes are both desired and unintended is going to be the focus of most of my remarks. I should also say that as a clinician myself and representing the American Medical Association, I like to think that we can offer suggestions of what I might call "news you can use." So, this will be very pragmatic in terms of how clinicians caring for patients can use these new tools in ways that improve care. Next slide.

So, our vision comes at the conjunction, at the convergence of artificial intelligence, and the quadruple aim. And just as a reminder for folks, the first aim is to enhance the patient experience of care. In this context, it means that patients' rights are respected. They are empowered, they are informed decision-makers, and they are truly active participants. Concerning improving population health, it is our view that healthcare AI and all the efforts surrounding it should focus on high-priority clinical needs and should advance health equity. That they should not perpetuate historical and some, we acknowledge contemporary injustices that are experienced by people in our country.

And third reducing cost. We believe that if you address these issues of inequities, that to follow will be a reduction in the cost of care. Not just to those who are paying for care at the government or the commercial plan level, but employers, care for individuals that we will see that there is more return on those investments we make as a country. And then lastly, it is important that particularly also exposed bare, I would say, with the pandemic that artificial intelligence, or as we might call it augmented intelligence, should engage people right at the point of care. So that they are involved in developing, implementing, monitoring, and improving these products over time. Next slide.

So, the framework that we have found advanced, and it is one that others who are interested in knowing more can see outlined in further detail on the AMA website is the three Es. The Ethics. The AMA is the steward, really the holder of the code of medical ethics. And so, a number of our ethical principles and chapters in that code relate specifically to the use of information and health equity.

Evidence. The mission of the AMA is to advance the art and the science of medicine. It depends on evidence. And we expect the same for AI products. That they will meet those standards from the beginning, and I was delighted to hear them mention earlier the approach that is taken by Picori. That if we are talking about caring for people, that people, patients, must be involved right from the get-go in deciding what gets done and also what that evidence needs to support. And then, Health Equity, I provide here, how we view health equity but probably a lot of words come nowhere close to reality the powerful image that we saw that came from the Robert Wood Johnson Foundation. Next slide.

This is an I chart. Slides will be available, I am told, on the website and this is also available on the AMA website. So, ONC's as well as ours. But the purpose of this is to say when something new, a new technology really of any kind is being introduced into practice and when those individuals, professionals, patients, others, are experiencing its introduction, there must be a clear definition of roles and responsibilities. So, who is responsible at the various stages of planning and development? Who is responsible for implementation and oversight? And to accomplish our goal of improving health outcomes, you need to have those responsibilities explicitly laid out. Many of them, as you will see on this chart, are shared by more than one of the key participants: developers, deployers, and physicians. And that you need to engage a diverse community of stakeholders throughout the process. Next slide.

So, the guidance that we have for physicians who are considering or are already in an environment where artificial intelligence or augmented intelligence products are used is three questions: Does it work? Does it meet the expectations that I already laid out for ethics, evidence, and equity? And can I trust it so that I can be sure, and as sure as possible, that it is safe and effective and if those parameters, those important characteristics change, that I can be sure that I will know about it as quickly as possible. Does it work for my patients? And this gets us to the issue of health equity by design. It is no help to anyone to have an AI algorithm deployed, leveraged in their care, if that algorithm does not apply to them, to their population which they are a member. The example recently given of artificial hearts not fitting women. They didn't fit children. Those types of concerns have to be addressed. And has it improved health outcomes? Next slide.

To take a bit of a deeper dive, and again more than you need to hear, and I will promise you I will not read this, but some key points here. Towards the bottom of the column for the AI system, I think it is particularly important that AI developers make sure their products are usable by the participants that will ultimately receive it, or benefit from it, or could be harmed. And that there be publicly available information about the data itself and the validation processes that were used and if applicable, that the product has received FDA approval or clearance.

On the other side ever the slide, the developer. There are only so many resources that can be devoted to healthcare. It is not unlimited. And so, are the products the predictive models, ones that will meaningfully influence care decisions and outcomes? Is there an opportunity that will be enhanced by that product? Some commitments are needed to data quality, data security to ethics, to the collection of the data itself. Do patients know their data is being used? And that many steps are taken to address bias and to ensure that the re-validation process takes those into account. Next slide.

Does it work for my patients? And so, this drills down to the notion that if I am an OB/GYN in practice and I am caring for women who are at high risk for adverse maternal outcomes because of their population characteristics, they come from the Black community, the Hispanic community. They do not have the same outcomes at least to this point. I need to know if that product has been evaluated in my care setting that it

reflects my practice and that it will be continuously monitored and that there will be ways in which my findings, my observations when it doesn't work well, can be communicated back to the developers. Next slide, please.

So, I am going to go next to three specific examples before I close of efforts at the AMA to advance health equity in the space that is related to data and coding, and technology innovations. So, the CPT, Current Procedural Technology, code set is stewarded by the AMA and there is no question that the collection of data and the coding highlight that there are disparate outcomes, particularly in chronic conditions but also during COVID for distinct, as well as intersecting marginalized populations. Our vision is that if the contextual knowledge is increased across disciplines, organizations, and populations that that will inform physicians and others who care for patients and will have the desired improvement in health outcomes. How are we doing this?

We have committed to addressing inequities in innovation such as differential access to technologies. Variations in adoption in use. Algorithmic biases that impact health outcomes. And we are casting a wide net to engage new entrants to participate in CPT as advisers and as innovators. The opportunity as we see it is to say that the current level of inequities can serve as a catalyst and so some recent activities have had to do with really lightning speed rapid response to the vaccine and testing advances during the pandemic. We are very supportive of changes in telehealth and remote care technology because then access to care is improved and we have issued an appendix that creates and disseminates an AI taxonomy because that can be used by innovators and developers and others to reflect changes in the code set. Next slide.

We focused a little bit but not as much has been talked about, or I have not as yet, talked as much as I would have liked about AMA's privacy principles. They are available at the link down below. But it is that any collection and storage curation use of data raises some privacy concerns. It is our view that there has been perhaps more responsibility for securing one's privacy that has been placed on the consumer, and that that should be shifted increasingly to those who hold the data and that it will be important to then look particularly at mitigation of harm. Next slide.

And so, to advance that, we have issued a resource for app developers so that they will see that privacy by design can be accomplished. We make the business case. We talk about how privacy controls advance equity. And a checklist for developers for translating into their products some of these privacy principles. Next slide. And then lastly, and I am seeing that maybe not the full slide came through, ah! There we go. Thank you.

I am the person who gets to show, I think it is for the first time, what we have announced this week which is a collaborative effort in full health. And it is an initiative to advance the really, the health innovation investment development and purchasing efforts going forward. And so, who are we interested in having joined this community? People who allocate assets should be investing in funds that promote health equity. It should also be the developers who we think have much to gain if their products promote as opposed to stalling equity efforts. The purchasers of those solutions because they then can be sure that the product will help the people they serve and various influencers in which I would also include organizations such as ONC and others represented in today's meeting. So, with that, I will close. Next slide. And refer people who are interested in learning more to the AMA's website where you will find several other efforts that relate to our health equity initiatives. Thank you very much.

Aaron Miri
All right. Next up is Dr. Dankwa-Mullan.

Irene Dankwa-Mullan
Thank you. Next slide, please. So, I am also grateful for the opportunity to contribute to this expert hearing and share some perspectives on Health Equity by Design means and what the ONC and HITAC can do to make health equity a core design principle of health IT. So, I am going to share some information on how we have promoted health equity across our organization, centered on health equity and racial justice principles along the dimensions of ethical AI in our technology development life cycle. And in providing the recommendations I will focus my remarks on how we can build a holistic healthcare system where equity is centered and deeply embedded firmly in our AI design efforts. Next slide.

So, in summary, health equity by design as a concept means centering equity, fairness, and justice principles in data and evidence generation in certain standards and promoting EHR interoperability in digital health and AI, machine learning, technology design, and development. Throughout our systems, throughout our programs interventions and policies through a collaborative multi-center approach. And this incorporates having timely and secure access to complete accurate and unbiased electronic health data that includes all relevant sources of health determinants data to optimize health outcomes for all individuals. It also includes having inclusive and human-centered design, development, and implementation of AI machine learning technologies and integrating all of these principles of equity and justice along the design process.

Fairness and transparency in data and design generation as well as accuracy, completeness, and development of the standards all will contribute to ethical and equitable health outcomes. The concept includes the development of high-quality relevance, social determinants of health data in certain standards. Addressing and mitigating bias in AI and machine learning algorithms by identifying all of the potential sources of bias and mitigating its harmful effects when used in public health, clinical, or healthcare decision-making. And finally, really establishing broadband connectivity as a social determinant of health with formal recognition and adoption of standards and policies including evaluation of broadband-enabled technologies to bridge the digital divide.

Addressing health equity by design is a multi-pronged, multi-sector approach and comprehensive requiring a strategic approach. Next slide. So, at IBM and IBM Watson Health, we have established a company-wide culture of health equity I am always proud to say that I have been in my Chief Health Equity role for the past five years. Our health equity by design efforts are inclusive, comprehensive, and includes promoting inclusive language in our technology to replace all discriminatory terms in technology with inclusive words. Establishing a design justice for racial equity to build diverse teams and promote inclusive design.

Tech-quity is promoted across the continuum of our AI and machine learning, and development life cycle, and this concept of tech-quity calls for all of our technology business to be accountable in the act of promotional health equity, promoting AI in algorithmic fairness, enhancing ethical and trust where the AI and most important, cultivating trust with communities. Building technologies for social good and sharing inclusiveness in all of the design is some of the important aspects of this work. So, we work with government figures, partners, and communities to identify these solutions and share that we are creating greater transparency, promoting better healthcare and care coordination, especially for those experiencing social bias and the disadvantage. Next slide.

How do we design better data and health IT for health equity? How are we designing robust data representations? To capture the complete life experiences and understand those data points that impact health outcomes. And I am going to share five aspects of bias across data generation, data science, and technology design and development life cycle. They are evidence, provider expertise, exclusion of data, environmental exposure, and empathy. And I will describe these aspects and sources in a little bit more detail in my next slide. Next slide. Thank you. Great.

So, the central challenges that we face today in addressing health equity begin with our science. Science-evidence base. How we translate the science and evidence to care for our patients, intervene in our communities, especially for those that are experiencing various barriers to optimal care. We do have an evidence bias and it stems from our research translation. The clinical decision is informed by the synthesis of evidence that is tied to clinical trials or real-world evidence studies. Now, what data makes up the evidence for the decision-making? Who defines what evidence is or should be? And it is well-known that the current state of our clinical trials and scientific evidence does not always match the demographics of the patient population who are at risk or suffer from the disease condition being studied. So, we need to set standards also in our science as well as our data and our evidence generation efforts for our health IT and machine learning and AI tools. Click again.

The next is expertise. Health providers, clinicians, physicians, expertise, and experience are really integral. It is an integral part of the translation that data or research or evidence into practice to result in improved health and outcomes. A patient can arrive at a medical facility with symptoms, but the primary care practitioner or clinician will determine the course of action based on their assessment and belief. It is often in combination with either lab or imaging data, pulling in guidelines and the actions can be based on a thorough examination of the patient, listening to their story, and understanding cultures, beliefs, life experience, but they can also include unconscious bias or conscious stemming from other experiences with similar patients or their stereotypes. And so, their actions can be influenced by what they think and so a healthcare provider's action can be influenced by their compassion, their sense of mission, and therefore this is essential if we are to promote health optimal health outcomes but because we know data never speaks for itself there is a human being deciding on how the data generated and how it is going to be used in practice. Click again. Yes.

So, the third aspect of bias is tied to the critical data exclusion in the research I talked about but also in our algorithms and analytic models. This includes lack of diversity, exclusion of clear information such as patients' needs and values, their preferences, and especially their life course experience and history, and how these determinants shape their health and outcomes. Bias can be introduced if we don't have these standards or the appropriate categories of race or ethnicity or gender, disability status, occupation as well, and the range of determinants of health that we know are linked to disparities or discrimination from quality healthcare. And the fourth aspect of bias is the influence of environmental occupation and I mentioned earlier life course exposures. These are social determinants of health that may influence health and outcomes. Equity goes beyond just providing this access to social needs. It includes access to resources, to opportunities, providing them with the empowerment that they need to drive health-promoting behaviors.

And a fifth aspect of which I always emphasize is data empathy and refers to how much empathy, patient values, and preferences, or patient reported experiences, are integrated into the care or in our metrics and decision making. And data empathy also includes knowledge or experience about the people, the places, the factors that made up that data. And lack of knowledge of these data sources or inability to recognize

that bias results in our inability to optimize the algorithm of our decision-making process. So, health data needs to be standard enough to be exchangeable globally across multiple platforms but needs to be human enough to convey the story, the experiences of patients and population. Next slide.

So, addressing deeply embedded bias in our health data to address the disparities I mentioned really requires a multi-stakeholders and strategic collaborative approach and one of the things that we can do within the tech industry is to align our ethical efforts with health equity by design and racial justice. And IBM we led the development of a framework for integrating health equity and racial justice into the AI development life cycle and this framework can be used by academic researchers, development stakeholders, to really assess the impact of their tools and ensure equity is prioritized in the implementation. Next slide.

I want to address the question about how we would build a system where equity is firmly embedded in everything we do as part of a holistic healthcare system and provide some concrete actions to create a path for inclusion and equity at all levels of the health IT marketplace. And I think that immediate needs is for data standards and interoperability starting with an honest assessment of our social mission of our goals, our objectives for health equity by design and in particular, those value drivers that we are trying to pursue. What are the organizational morals and ethical imperative? What is the current state of our data sources and data architecture and where and how do we need it to evolve? And the next steps actually really prepare the data and why data? Because we know data is the lifeblood of any machine learning or health IT solutions and it requires several key steps that is on the slide. Like really breaking out of organizational silos for integration across the enterprise. Making sure our data is diverse and comprehensive and accurate. And managing unintentional bias or conscious bias and its potential ethical, social, and legal concerns that it has not only for our algorithms but for our science and evidence generation.

My last two slides provide eight recommendations for ensuring the success of health equity by design. In summary, we need to implement digital health IT platforms and an infrastructure that can really leverage all these millions of data points and deliver this integrative equal system of health, mental healthcare that is tailored to diverse patient populations. Because data we know is the foundation of all of our health IT and so building-integrated healthcare system, harnessing their power of real-time data to build health equity dashboards, some of the activities that we are implementing currently at Watson Health are collecting and tracking health equity sensitive metrics. It is also important for health IT tools and AI machine learning tools to make sure that we are enabling connected seamless and simplified healthcare experiences. That will really facilitate meaningful, equity-focused, value creation workforce. And basically, interaction for when and where and how patients, as well as clinicians and administrators, can access this tool through visual interactive health equity dashboards. Next slide.

The next slide shows the last four where we recommend also promoting data responsibility and data empathy. And developing social determinants of health standards. In terms of that, we want to capture the complete picture of the patient's health and life circumstances including the communities and the workplace, because we want to anticipate their needs and coordinate care more effectively. For example, a better understanding of a patient's circumstances which led to a no-show for an office visit or led to re-hospitalization or inability to fill their prescription in a timely manner. So, a patient perspective sometimes of their priorities or social needs may differ from our perspective of social needs for them or what is needed for health-promoting behaviors. This would also recommend optimizing administrative and clinical efficiency and promoting equitable access to ensure the success of our hybrid care system which we are using right

now in this age of COVID. So, addressing disparities in broadband access and the lack of connectivity are all-important recommendations.

So, I would say addressing embedded bias lies in the conduct of our research, in our evidence base, in our practice, and our policy and requires a systematic, coordinated, and collaborative approach. We all need to bring humanity and empathy into our science, into our practice, into our research, and work collaboratively with all communities to inform these data standards in a framework for responsible data and empathy and ethical AI. So, thank you so much for listening and the opportunity to present to this committee.

Aaron Miri
Thank you very much. All right. Next up is Dr. Ziad Obermeyer.

Ziad Obermeyer
Thank you so much. I have a somewhat non-traditional presentation in that I do not have any slides, but I am going to post into the chat a link to a document that I hope will be helpful that I will refer to and some of my comments. But I wanted to start by actually just saying I am a practicing doctor, and a lot of my work comes from the perspective of someone who wants algorithms to succeed in medicine in my clinical work as in my work and health policy, I think I like all of you have seen a lot of really tough decisions that humans are faced with. And there are a lot of ways in which algorithms can be incredibly helpful for helping us make those decisions.

I have this optimism about artificial intelligence and algorithms that I hope, at least, some of you share but I also have this deep sense of caution because if we want to get to a state of the world where algorithms are meaningfully helping us to make decisions, we have to be so careful to avoid the huge pitfalls around racial and other kinds of biases in health equity in general. What I thought I would do with my time is walk you through a concrete example from our work that I learned a lot from and then draw out three lessons that I hope will be useful to all of you in your organizations and potentially to ONC.

Here is the example that I learned a lot from and that we got a lot of attention from the press as well because I think it captured something deeply problematic about the healthcare system. And this is an algorithm that is widely used in population health management. In population health, we have all of these resources. We have nurse practitioners who can make home visits. We have extra primary care slots, and we want to deploy those extra resources to people who are going to benefit from them. That we will be able to help keep healthy if they get those resources. Of course, we cannot give extra primary care to everybody. So, we have to target those resources wisely. This is one of many examples in healthcare we have a limited, scarce, precious resource and get it to where it is going to do the most good.

This is a great, great use of algorithms in general. Algorithms are very good at, for example, looking into the future and seeing, okay, this person looks okay today but they are headed for an exacerbation of congestive heart failure or COPD or some other chronic illness. If we can get them into the system today. Get their medications in order and get their primary care to take a hard look at them and figure out what they need, we could do two things. We could prevent those exacerbations of chronic illness which is a win for the patient, and we could save the healthcare system all of the money that comes from the ER visits and the hospital care and things like that. So, great use for the algorithms that do great work in predicting traffic and predicting what we will buy on Amazon and watch on Netflix. Those same algorithms can do this task very well.

So, the particular algorithm that we study was one made by one company and this company is one of the largest developers in this space. This algorithm is used for decision-making for 70 million people in the U.S. every year. So, the scale is huge. The family of algorithms works the same way designed by other companies but also academic groups, parts of the Federal Government, but 150 million people every year. So effectively, the majority of the U.S. population is being run through these algorithms every year to decide who gets access to population health management resources.

What did we find when we studied this algorithm? We find an enormous amount of racial bias. So, what we did was we looked at the patient with the same healthcare needs so the people who had the same likelihood of having that exacerbation of heart failure or COPD and we compared Black and White patients. What we found is that at the same level of healthcare needs over the next year, Black patients were assigned a lower algorithm score and that meant that Black patients were deprioritized for access to these population health resources that they desperately needed. And the scale of this bias was very large. What we found is that in the highest priority group, the ones that would get fast-tracked into a high-risk care management program and get all of this extra help with the healthcare, an unbiased algorithm would have doubled the fraction of Black patients from about 20% to 50% in that high priority group. The scale in our healthcare system is hundreds of millions of people and the degree of bias was very, very large.

So here is my first lesson for equity by design is that if we are serious about equity and we are serious about building that into the design process for algorithms and what we do with algorithms, the starting point is we need to define bias. There are a lot of different definitions and there are a lot of metrics that you can calculate. There are code packages that you can run over your algorithms and calculate all sorts of fairness metrics for different groups and things like that. All of those, I think, have their place and they are very helpful for specific things, but none of those things is a substitute for looking carefully at what the algorithm is supposed to be doing: defining bias and measuring it. And that approach is grounded in the law and one part of the law in particular which is disparate impact.

Let me just walk through that in very crisp detail so it is super clear. In this population health management setting, what are we trying to do with the algorithm? We are trying to prioritize people who need help with their healthcare needs and get them access to extra resources. So, what does bias look like in this setting? It is not about the fraction of Black patients in my training data set. It is not about anything about the inputs. It is not about whether the algorithm uses race in reaching its judgments. It is about the score that the algorithm gives relative to the needs that the patient has. My algorithm should be prioritizing people based on their healthcare needs when I look at the scores, two patients with different skin color colors are going to have different scores even when they have the same healthcare needs. That is our definition of bias in this setting, and I learned a lot about how to define bias in other settings.

First, articulate what the algorithm is supposed to be doing, hold it accountable for that and compare the scores that are being assigned holding constant the ultimate purpose of the algorithm for different groups that we are interested in. That is the first lesson and I wanted to point out that you do not need to open the black box to apply this lesson. You only need the output of the algorithm. The score that the algorithm assigns the patients and you need that measure of what was their actual need? What is the algorithm trying to accomplish? Prioritize people with high health needs. That approach has resonated with a few different audiences. Perhaps most importantly I am working with State Attorneys General who are engaged in investigations of algorithmic bias in their jurisdictions and this approach is proving very powerful because it resonates with Civil Rights law.

I have also been working with several other people in the industry in health insurance and healthcare systems and tech companies who are building algorithms and find this very crisp statement of bias incredibly helpful so they can avoid it in their work. That is lesson one is to do something about bias. We first need to define it and that definition needs to be grounded in a very specific metric of what the algorithm is trying to accomplish and that aligns our definition of bias with Civil Rights law. The second lesson I wanted to convey is now an optimistic one which is that this bias can be fixed. So, in this case, we worked with the company that developed this algorithm to fix the algorithm and we have done similar work with several other players in the healthcare system since then. Again, I will walk through this example to show you how we fixed the problem.

In this case, algorithms were predicting, they were supposed to be predicting who needed healthcare. What were they actually doing? Well, what they were actually doing seemed reasonable. They were predicting which patients were going to cost the healthcare system a lot of money because they go to the ER, and they go into the hospital for management of their chronic illnesses. The algorithms were predicting healthcare costs as a proxy for healthcare needs. That's not unreasonable because those two things are correlated. But it is very biased because Black patients and a range of other patients who are underserved face barriers to accessing the healthcare system and they also face racism from the healthcare system that results in different treatment by doctors, by nurses, by everyone else in the healthcare system and that is very well documented by several research that has nothing to do with our research. This is well-known. Predicting costs is a biased choice when you are trying to find people who have healthcare needs. And that is a very common problem in algorithms and not just in health.

In criminal justice, for example, we often see people are trying to build algorithms to predict someone's likelihood of committing another crime. But we don't look into people's hearts and see their true propensity for committing a crime. We look at their arrest record or their conviction record and those variables are incredibly biased because of the different attention that different groups get from the criminal justice system and because of the bias built into that system. Wherever we are working with algorithms as they intersect with society, we will face these problems of the variables that we have for the algorithm to learn from can be incredibly biased and we need to be very careful about our choice of what we teach the algorithm what we are telling the algorithm to learn and if we are telling them to learn about healthcare costs they will miss all of the costs that should have happened but did not because the patient could not get a ride to get her breast biopsy because the patient symptoms were dismissed in the emergency department, and she never got an MRI that would have shown a small stroke.

For all of those reasons, we cannot be in the business of using healthcare costs to predict healthcare needs. Once we realized that, the fix was very easy which is we assembled a range of metrics of healthcare needs and used that to train the algorithm instead of healthcare costs. That's a lot more work because you need to assemble all of the indicators for chronic illnesses. You need to deal with the fact that not everybody has a hemoglobin A1C and not everyone has a blood pressure recorded. Those kinds of data issues what are makes good algorithms work and those are the kinds of things that can turn algorithms from tools that re-enforce structural inequalities into tools that fight against them and get resources to the people who need them. So that is the second lesson is that once you have documented bias you can start to understand where it comes from and how to fix it and in almost all of the cases where we found biases by working with collaborators, we have been able to re-design algorithms to fix them, but it all starts with that definition of bias and understanding where to focus.

The third lesson I wanted to share with you is also outlined in that playbook. In our work with all sorts of actors in the healthcare system from insurance companies to hospital systems, to others, we have aligned on a specific set of institutional measures that real organizations can and have put in place to prevent bias from emerging in the future. Someone in the C-suite of an organization needs to have responsibility for algorithmic oversight. Right now, the responsibility for algorithmic oversight is diffused. It is shared between IT, some parts of the business-like population health management, a lot of other things. So, when a lot of people have responsibility for something, nobody has responsibility for something. Someone in the C-suite, someone who has strategic responsibility in the company, needs to be the point person for algorithmic accountability. That person needs to have a process and an advising team that is made up of a lot of diverse people from the community, from communities of color, et cetera, so that they can flag problems and bring it to their attention and so that person can do something about it.

Companies also need to maintain inventories of all of the algorithms that are being used in their organization and they need to collect very clear metrics of performance against the ideal target of the algorithm. What is it supposed to be doing a question for all of the protective groups that they care about and take care of in their population and those kinds of documentation requirements, which are pretty standard and a lot of other industries, are absent in this area of health. So clear documentation standards are really, really important.

And the last thing that I wanted to say which I think is hopefully useful for the people at ONC is that one of the reasons that companies are not investing in these measures is because they do not know how to invest. They are not getting guidance from the government, from law enforcement about what bias is and how to avoid it. There is a lot of confusion I think in a lot of different places about how we measure bias and how we define it so there is no alignment from the industry because there is no guidance in coordination from governmental agencies and so I figured that since it's the Office of the National Coordinator then coordinating these kinds of things would be a key part of what we want to do. Let me end there and again refer you to the algorithmic bias playbook where we go through some of the concrete examples and some of these very specific measures that organizations can take to prevent and fix the bias in the algorithms they are using.

Aaron Miri
Thank you, Dr. Obermeyer. Great overview and great lessons. I appreciate that and the link. I was checking that out. Excellent stuff. Okay. Next up, Dr. Nicol Turner Lee. Dr. Lee, maybe you are on mute.

Nicol Turner Lee
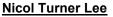I am here, but I do not know if I am a panelist. Can you hear me?

Aaron Miri
Yes.

Nicol Turner Lee
Okay. Can you see me?

Aaron Miri
Yes.

Nicol Turner Lee

Okay. You can. I cannot see myself. Perfect. I cannot see myself on the screen. I do not know why but I will start talking if you can actually see me and hear me. Good afternoon, everybody. I am very happy to participate. As it has been mentioned, I am Dr. Nicol Turner Lee, I am a Senior Fellow in Governance Studies at the Brookings Institution, and I am also the Director of our Center for Technology and Innovation. And I am excited to join with one caveat, as my previous presenter mentioned, I am a sociologist, I am not a clinician, so I am an outlier and I do not have slides, and I am going to go through some of the work we are doing at Brookings that applies to the health equity space.

We do work at Brookings at CTI on a variety of policy issues. One of them is around regulatory concerns when it comes to what has been spoken about, the digital divide. In fact, I have a book coming out on the U.S. digital divide that touches upon issues related to telehealth management before the pandemic and then throughout. In addition to that, I also focus on a lot of work-related to artificial intelligence, particularly machine learning algorithmic bias and I am particularly concerned about that as a previous presenter has mentioned because my work at Brookings intersects race, technology, and social justice.

I want to use my time today because I think the previous speakers have provided some great context for how we understand how machine learning algorithms integrate with the type of systems that we want to do when it comes to health equity by design. I want to push it a step farther and at the end of this presentation offer more pragmatic solutions and some of which I am working on as part of my portfolio.

Let me start by saying, that health equity by design in the health IT area is a hard question to actually solve. And I will tell you why. Because we do not necessarily have health equity by design generally when it comes to the time of care and health in digital inequities that are experienced by medically marginalized communities. When I think about the work that I have done in the space of health IT, dating back to when I was actually at the Joint Center for Political and Economic Studies when we ran a health disparities project, we were talking back then about how to leverage technology when it came to SMS text messaging services or using various voice communication services to interact with clients or patients simply because we knew that they had very limited proximity to quality healthcare institutions and many of those existing patients had a suite of either chronic conditions or co-morbidities that unfortunately were unsettled with the introduction of COVID-19.

With that being the case, my friends, one thing for sure is that we do know when we have access to technology, that it can open the door, I think, to some possibilities of closing some of the health disparity gaps. We have a paper coming out in the next few weeks at Brookings that will look specifically at telehealth, and we talk about these indices, and I call it care equity, health equity, and digital equity, and how we roll that out as a plan to ensure that medically marginalized people have access to real-time and reciprocal care. With that being the case, today's topic is artificial intelligence. I want to do a little bit more of my conversation around data quality and in particular talk a little bit about how that impacts the models that we are designing and executing in the space. And then I will leave with pragmatic recommendations for the rest of my time.

The first thing I would like to say when we talk about the social determinants of health is that we have to understand that the data that we will use in any computational model will be traumatized. Dr. Rene Cummings at the University of Virginia used the term have taken a liking to when it comes to talking about disparities in any type of data set whether it is criminal justice, health, or education when it comes to AI,

she uses this concept of what is called trauma, data trauma. And what she means by that is that any data set that we may potentially rely upon to train any type of machine learning model will come with historical inequity and systemic inequalities baked into it because the data we are pulling from has in its own way its own scars and wounds that is highly impossible for us to disentangle through the use of machines only. The type of embedded discrimination as mentioned previously to me that is actually showing up in many of these data sets.

With that being the case, I think she makes a great point and for those of you watching, when we talk about the social determinants of health, it is very important, and I like the way one of the previous speakers talked about data empathy, but it is also important for us to have consciousness when it comes to the fact that our data will not always be infallible. I am a social scientist and one of the things I constantly argue with when it comes to technologists is I am not in a rush to market, to generate the next idea. I have to deploy, like many of you in the medical profession, care, duty of care when it comes to the use of data and the handling of human subjects. I think in any initiative, and this is particularly relevant to the ONC, that there has to be some type of data quality statement. One in which recognizes the type of trauma that comes with particular populations, but more importantly, comes up with ways to either develop new data sets, oversample or tease out the under sampling of communities that we need their information to do this right.

That is the thing about machine learning algorithms that excites me in my work. There is a sense of optimism when it comes to the efficiencies that we get with computational models that think faster than any of us on this call. But there are the dangers of computers actually surveilling our data in ways that can create a greater precision of discrimination. Much as it was mentioned in the sample of the healthcare algorithm that relied on hospitalization thinking it was blinding the algorithm of any type of bias, in actuality, it was creating or recreating the systemic inequalities that come with the lack of access to quality health insurance and quality care.

One more point I would like to say when it comes to data trauma, you cannot tease out the trauma that is embedded in the data we are relying upon, my friends, when we do not have diversity at the table. And I am a true believer that diversity comes in all shapes and forms. It comes from the standpoint of who is developing the model, in terms of who is listed that sits and interrogates that model, based on their lived experiences that they bring to the conversation. And what subjects are we reaching out to ensure that we are gaining the right feedback during the process? I think we often overlook that we are not just talking about cultural agenda diversity, my friends. We are talking about an interdisciplinary context and interdisciplinary friends that come to the table. Sociologists like me understand a little bit more about the historical circumstances that come with the variables that we are inputting into these black boxes that have sociological implications in the end.

I wrote a paper, and I will put it in the chat, that was perhaps the longest paper I have ever written. It was with a lawyer as well as an engineer and I am a sociologist. Go figure why it took a year. One of the greatest experiences that I had actually done that paper with people from other disciplines is that it actually forced me to think differently, both from an intellectual perspective as well as methodology. I would suggest to the ONC as you think about ways in which you are embedding equity into the design of health products who is at the table matters both from the perspective of the designer, as well as the subject. And having that accountability to check on the lived experiences being represented in those databases or underrepresented matters.

Give you one more example of that before I get off my soapbox. We think about criminal justice algorithms, it is not so much they do not work with a great per significance about accuracy. Well heck, they should. The data represents people who have been over incarcerated, and mass incarcerated in this country, Blacks and Latinos that show up more often in the system. What I say to people, in that case, is that means that we are actually using data sets again with the historical trauma and we are not able to tease out where that underrepresentation or overrepresentation occurs. And you just cannot do that with technical cadence.

My second point after we look at and interrogate data quality is that we pay close attention, and I like the way it was said previously, to how we are defining bias. I have concluded that bias is pretty normative. Computers do not discriminate. We do. We come with our values, norms, judgments, and assumptions about the world, and explicitly and implicitly they find themselves in our models. And so, we have to not only check ourselves, but we also have to remember those foundational concerns, and in my research, we consider the bias to be when similarly situated, similarly situated people, places, and objects receive either differential treatment or as it was mentioned our disparately impacted. What does that mean? LaTonya Sweeney and I will give you a non-health example to get your mind right on this, has suggested that on the internet in the search for employment people with Black or Latina sounding names tend to be kicked out of the suitability pool when it comes to applications. If your name is Latoya, LaTonya, Juan, Rodriquez, just like we said in sociologists that your address, your zip code, these other proxies factor into whether or not the prediction is going to lend itself to your inclusion.

We have to figure out in this world of health equity whether or not, I think it has been nicely said so I will not glean too much on this, whether or not we are disentangling those proxies that lend themselves, not just to the differential treatment because of the sound of your name or where I may live in terms of my proximity to healthcare, my transportation availability, but whether or not we are thinking about the disparate impact. When my colleague before me talked about the healthcare algorithm, the challenging thing of being assigned a risk score despite having chronic disease because the variable focused on how much I pay into a hospitalization, the challenging thing is we are not solving anything. When we kick people who need the program out the most because we are using blind variables to somewhat suggest that we are not being discriminatory.

Friends, as a sociologist I tell people all the time. This is a normative process. And it requires us to better interrogate these models. And what that means is that we have to interrogate on a variety of primary, secondary, tertiary instances whether or not the algorithm as it has been stated is performing to standard. The problem that we have is that we often do not know if the algorithm is actually performing to standard and we come in and we correct these mistakes once they foreclosed on opportunities for other people. And that is where again examples of bias and well settled in the literature I think to point us to the space where we have to interrogate both the technical cadence and the outputs that may come and really put on our hat. I like the way it was said, we are doing a lot of work at Brookings on this, whether or not we are creating disparate impact and excluding populations who very much should be part of the conversation and dialogue.

I recently did a training for the Center for Disease Control and one of the things I was suggesting to them is that you need to come up with a body of work that is an agreed-upon framework for your interrogation process. If you come out of the gate, as most technologists do, and you ideate and create with the idea that you are going to engage a permission list of forgiveness, we are sorry that this algorithm kick out all of the Black patients that were probably eligible for the program, what we essentially are doing is using this tool

as another mechanism of inequality. And that to me is this interrogation process is an area that I have been very, very closely tied to in the last few months.

I would say the third thing before I get to more pragmatic stuff and wrap up so we can keep going, is that we think about the feedback loops that we have installed in this health equity by design process. Oftentimes we are talking to ourselves. I am actually talking to myself right now as I am looking at this screen and I am looking at Aaron because I cannot see my face. But what that suggests is that we have to figure out, my friends, how do we get feedback when it comes to the feedback loops from our patients and our clinicians.

Our other stakeholders are part of this process. I have a chapter coming out in a book is that around an incentive-based rating system that allows us to think about the algorithmic economy in the same way that we think about other rating systems that allow us to check the predictive capacity of that model but give other people the chance to say that is me that is not me. And the extent to which we develop what I call these feedback loops, and I will be honest this model was based on my buying a dishwasher a couple of years ago, when I walked into a big box store with and was immediately taken by the big yellow sign that is required by the environmental protection agency that outlines the purposes of warning you the electricity use of that particular device. That assured me that there was some conversation among standard bodies like NIST, like EPA, like the Federal Trade Commission, and other community and business stakeholders who make sure they were getting this right. That we were putting durable consumer products into the hands of consumers.

I think what we have found in the machine learning algorithm space is there are no checks and balances, and we are not quite sure until there is a reputational risk whether or not that algorithm is creating harm. And the piece of work that I am publishing in the next few months is part of a book that is really getting us to think about incentive-based systems that drive, not only the marketplace in the private sector but the public sector or use cases to have some better awareness as to whether or not these are working effectively and fairly.

It is the hardest thing as I wrap up to monitor and measure fairness. What is fair to one group of people is not fair to me. I am looking in the chat and somebody said I was screaming. Well, I can't see myself I do not know what my voice is doing because I do not have an assessment. That is the same way that algorithms work. They go out into this world, this space where we don't know that they create harm until it comes back to us. If you are in the government sector, here are my recommendations, and you are taking on health equity by design and integrating machine learning algorithms, you have no right or choice to walk in with eyes closed. You have to go into these scenarios from the development stage and the procurement stage with your eyes wide open.

Here are some things I would like to put out there for ONC to keep thinking about. First and foremost, you got to come up with a framework for how you interrogate these models. It can be a repository of best practices, it can be a set of criteria, but you need a checklist. We call it in our paper because we know that there are a lot of checklists in terms of accountability, once the algorithm has been deployed, we call it a pre-impact statement or assessment. What is it that you are checking the boxes on? Were there enough people with lived experiences at the table? Does the sample have a level of data quality versus trauma? We are working on those lists at Brookings to help us interrogate this model from the onset. I think it is important to be included on that checklist as a pragmatic response. Where do you assess privacy and fairness? Where does privacy show up, ethics show up, and do you have some type of control meter

that says this is an ethical path forward? Or do you need to go back to the drawing board and bring more stakeholders?

The third thing I would say is we need to include humans but not humans that look like us. We need humans that represent the heterogeneity of the model we are creating and the world in which it is being contextualized which is another topic to speak about. Then the last thing I would say is we need to employ technical and social cadence in health equity by design modeling. What does it look like to be a technical factor? How should we be looking at the noise on the technical side? What should engineers or data scientists be thinking about when they are put in certain proxies? Regulated industries like banking have litmus tests for inequity. We do not have that necessarily in the healthcare space. So, what does that look like to just suggest that the switching out or replacement of proxies can generate either that differential treatment of subjects, places, objects or disparate impact?

Then I would say the last thing, of course, none of this would work if we don't close the digital divide. Even where people access the technology and this is the last thing I will say, I promise. Is that we have got to be sensitive. That most people that we are trying to give equity to are accessing technology in public spaces. So, the extent to which quality is not only traumatized but is not necessarily as open because the places in which we are involving people because of the digital divide to register the health data is not where you or I would register that information. So, we have got to break down the digital divide not just by bits and bytes. By whether or not we are giving people good quality and pathway to engage this science differently. I will stop there. And leave it to the next person because I know we are almost done and thank you so much for having me. So tough to go last or almost last.

Aaron Miri

No, Dr. Lee, my goodness. What an amazing, moving presentation. Thank you. You did it with the extra bonus points of not seeing yourself on screen. So, thank you, very, very, very much. All right. Next up is Terri Willits, let us close it out strong, please.

Terri Willits

All right, well, thank you so much for having me today. And everything that Nicol and Dr. Obermeyer were talking about is music to my ears for sure and thank you for opening up this type of conversation about health equity. The title alone tells us that we have to be intentional. That we have to think through the implications of what we are doing. And health equity by design must be at the center of our healthcare programs and our strategy.

And so, when we think about health equity, what does that mean to Anthem as a large healthcare insurance carrier? Health equity means that everyone has a fair and just opportunity to be as healthy as possible. We have heard this quote several times throughout our meeting today by Robert Wood Johnson Foundation and it is something we are truly taking to heart. Advancing health equity does not happen by chance. You have to be intentional about it. It requires intentional efforts to design and deploy programs that will address those unmet needs of populations and the root causes of systemic inequalities.

We have also heard that 80% of health outcomes are influenced by non-clinical factors such as nutritious food, reliable transportation, quality housing, and financial stability. And meaning that most of our healthcare is driven outside of the doctor's office. And so, when we think about equity by design, a strategy, you know, we are working to apply our equity principles across the quality improvement program. The quality

performance measure at population levels and stratification by race, ethnicity, and language, the quality improvement through member identification per programs or interventions to help mitigate bias, and program evaluations to include disparity care analysis, and to make recommendations for correction if potential adverse biases are identified.

When we think about those experiences in using AI to help improve healthcare or inclusion of health equity, you know, the current healthcare system is often disconnected. It is reactive versus proactive. It is often not personalized. We heard about this earlier with equality versus equity. And AI is a powerful vehicle that can better inform our stakeholders and help improve outcomes and health equality and health equity. Anthem is developing AI-based solutions to help improve the healthcare experience. One example is guided care experiences for care coordination, care management, and supporting decision making by informing care options to providers, care management, and supporting decision making by informing care options to providers, care management channels, and members.

So, when you build a close loop AI system over time, the accuracy of that system continues to grow, and the experiences continue to influence positively influence the accuracy of the algorithm. And when you think about the gaps and the data that we have been talking about, there are gaps and inaccuracies and data, and those gaps and inaccuracies could result in unintended consequences. This is just, we are singing with the choir because we have recognized this is something that needs a deeper dive.

We encourage healthcare stakeholders to launch a responsible AI program that consists of cross-functional participants and that this can offer a mix of governance, processes, checkpoints, training, and monitoring that support health equity. And we were just talking about the checklist so that is definitely something that we would encourage is forming a checklist which is the minimum standard documentation, and it is a great guide as well.

So, one thing you may recognize this, this is actually Dr. Obermeyer's book that he was talking about earlier, his playbook. And we have utilized this quite a bit within Anthem. So, when we think about what we see as the biggest impact that will shape future directions, we need to be intentional about driving essential conversations and actions to address these health inequities, healthcare, ecosystems are built on data. We need data to meet the three Cs which are to be correct, complete, and comprehensive.

So, without complete accurate data, the accuracy of AI decreases or even could produce adverse impacts. So, when we think about those, what we would like ONC to advance related to AI equity by design, we recognize the efforts, the joint support between CMS and ONC for the interoperability rules for improving the standardization of data collected and moved, which will help and expand the data sets that healthcare AI uses both in AI and non-AI focus approaches. We need to ensure more enriched data collection. We ask ONC to include all relevant stakeholders in updates in the interoperability initiatives including community-based organizations. We ask for continued updates to data standards for important social drivers and demographic data.

And finally, we note that there is a learning process here. This is a new domain for AI and responsible AI, and we will continue to evolve. And for ONC support and engagement, all parties, developers, medical communities, patients, and in discussion on how to advance appropriate data collection in use and how to reduce disparities. Thank you for having me here today. I appreciate the opportunity to speak alongside some of these most passionate people I have seen, and it is a thrill. Thank you.

Discussion (03:04:04)

Aaron Miri

Incredible. I wish Zoom had a standing ovation emoji for all of you. I am like motivated, go! I want to run a marathon. Let us open up for the HITAC comments and questions and folks that have feedback, please raise your hand. Anybody with comments or questions, please. First up, I see Dr. Luu.

Hung S. Luu

Those were fantastic presentations. I commend the panel for their passion and bringing this very important issue to light. This is near and dear to my heart because of the fact I do think that AI and machine learning hold a promise of helping to make healthcare more efficient and hopefully more equitable, but I think there is work to be done in terms of the data elements that feed into some of these algorithms.

I think that in particular, one area that I am very hopeful fortunate the future because of the work of the Gender Harmony Project is how we capture sex and gender preference because right now the system is rigid and binary. And the inaccurate capture of transitioning or patients who have gone through gender reassignment surgery, the information oftentimes is incorrect and that could lead to detrimental effects for them if that is fed into an algorithm that is a black box that nobody checks on and that could lead to increased health disparity, especially in this vulnerable population. I think that part of what we can do is to make sure that the information captured is accurate as possible.

Aaron Miri

Thank you, Dr. Luu. Thank you for your comments. All right. Eliel. Next up.

Eliel Oliveira

Thanks, Aaron. I want to piggyback on Dr. Luu's comment and mention also, the situation with race since we are talking about standards and race is so important. What is that clear definition? For most systems, it is probably going to be five types of races defined but if you look at other definitions out there you can get 100 or 90 different ones and I am posting here the **[inaudible] [03:06:45]** browser that was put together a while back ago just as an example. And I think there was some comment about genetics in the determination of race, different levels there on how to define race.

And lastly, one comment I will make is a study I saw a while back about ten years ago where IBM Watson was able to diagnose somebody with a rare cancer that clinicians were not able to do so and the reason for that was because it came down to race. The person was a Pacific Islander and there was a specific chancer that occurred in that region. So, the self-reported race may help a little bit, but the individual may be looking at them as they see themselves in the mirror. So, genetics may play a role. So, there are several levels here in the determination of race that I think we need to look at in terms of defining what is that standard we will follow nationally.

Aaron Miri

Good points. Great points, Eliel. It is an emerging area. Dr. Briggs-Malonson.

Medell Briggs-Malonson

I just wanted to piggyback on what Eliel was mentioning because I think that's a really important piece. For instance, one thing that my institution has done when even capturing patient-reported demographic

information is that even though you have these high-level race categories even defined by for instance CDC there are multiple levels two race categories there as well to become even more fine-tuned to allow patients to self-identify as they see best. Of course, also if you are bi-racial or multi-racial, you can collect all of those or identify that as well.

So, this is an evolving area of when do we use not only high-level race, for instance Black, White, Asian, Pacific Islander, Indigenous, all of the standard five, but most importantly when do we also use more of the subcategories which are even more specific. So, for instance, me as an African American, I am a descendant of slaves in this country, but I still identify as Black and African American there may be someone else who identifies as Black, but they are not a descendant of slaves here in this country and the lived experiences, as well as the multiple societal influences, are very different that contribute overall to health.

So, there are various factors that we can be thoughtful on how do we capture this data to make sure that we are providing the most equitable care while not making assumptions just because of what we assume someone's race or ethnicity to be which may not correlate at all directly to their overall health. This is just, I wanted to say all of these points are so incredibly well taken which shows the continual work we need to do to ensure that we are building the best processes algorithms that do not actually perpetuate bias but most importantly are helping us move along to achieve equity.

Aaron Miri
Great, great points there. I want to do a time check here and I know we have a stop at 1:30 for a break and Dr. Obermeyer, you raised your hand, you may want to comment very quickly. I wanted to put that out there, we have about a minute here if you want to have a word in.

Ziad Obermeyer
Thanks. Very quickly, love all of this discussion about all of the categories that we could and should be using and I think all of the intersectional categories that that would then imply is super important. I also just wanted to point out that currently, most organizations are flying completely blind in this area. For example, most insurance companies do not know anything about the race or ethnicity of the people that they are covering. I think part of the problem is that they are afraid to collect that data because they are worried that might be accused of using it improperly. And I think that is another area where articulating guidance from the government on the fact that it is okay and in fact it is good to have data because that lets you quantify disparities and the people you are covering will be really important.

Aaron Miri
Good point. Do not let the fear of litigation or others stop you from doing the right thing and what is good medicine. Great, great, great point. Well, panelists, my hat is off to all of you. An unbelievable discussion today. Taking us right to our time for a break. But I just want to say again, echoing everybody in the chat and plus ones and kudos, all of you rocked it, so thank you very, very much. Incredible, incredibly helpful discussion. Denise, anything you want to say really quick before we go to break?

Denise Webb
Just ditto. It was excellent.

Aaron Miri

Hats off. All right. So, HITAC team and folks listening in, we will take a break for approximately 15 minutes returning here at 1:45, or sorry, 1:30, no it's 1:30 now. So, 1:45 p.m. and we will go from there. So, 15-minute break.

[Break]

Mike Berry

Thank you very much and hello. Welcome back from our break. We are resuming the March HITAC meeting and the Health Equity by Design meeting and I would like to turn it over to Denise to get us started.

Content and Exchange of Data, Part 1 (03:12:06)

Denise Webb

All right. Thank you, Mike. We will begin our third panel and this panel is on Content and Exchange of Data, Part I. And we have four presenters, Denise Hines, the Executive Director of the Georgia Health Information Network, Dominic Mack, and Dr. Mack, who is the Director of National Center for Primary Care, Morehouse School of Medicine. Angela Thomas, Vice-President of Healthcare Delivery Research, MedStar Health, and Andrew Hamilton, Chief Information Officer, AllianceChicago. So, I will hand this over to Denise first and each speaker has 15 minutes.

Denise Hines

Thank you and thank you, everyone, for having me here today to share my insights. Let me start by sharing the experience of a pediatrician who is in our HIE community. His practice serves three rural counties in northwest Georgia and more than 60% of his population is on Medicaid and over 50% are minorities. He is unable to give us an exact number of the number of minorities because he has limited choices of ethnicity and race found in his EHR. He has cross-trained his staff to work with his patient families to fill out a questionnaire related to social determinants of health. It is on paper. So, some of these questions include, "Do you need help paying for transportation, diapers, rent?" "Are you homeless or worried that you might be in the near future?" "Are you abused or is someone threatening you?" "Do you need help finding a job?" "Do you need help getting your GED or enrolling in college?" "Is your need so immediate that you need food delivered to you tonight?" "Do you need help with counseling?" "Do you feel lonely?"

As each of us can imagine that any answers that are yes to those questions, create the need to capture this information in the HER, yet it is even more challenging or near impossible to enter that information in discreet fields. These patients who screen positive for needs are then referred to his care management department, keeping in mind these are also the same cross-trained employees that are running the front desk and other areas. But this care management department then continues their outreach to the patient caregivers and parents to continue gathering information.

Generally speaking, the needs include mental health and financial difficulties. Financial difficulties represent about two-thirds of the needs in that community. So, these same employees, who have also been cross-trained to do multiple jobs in the practice, created a pediatric foundation that can assist with food, clothing, diapers, wipes, hygiene products, and his office personally worked to create partnerships with local churches, schools, stores, and pharmacies to help assist them. But that is still not enough. They may also

need to provide air mattresses, fans, heaters, prescriptions, funds cover prescriptions, and even taxi and gas money.

So how about we take that scenario and talk about what this pediatrician needs to be effective. He needs more standards developed to allow for the interoperable capture to share the social determinants of health information. He wants EHR vendors to develop programs to store and retrieve information such as behavioral health and social determinants of health. He wants to be able to share this information, this critical information through the statewide health information exchange network, and for Georgia, that is the Georgia Health Information Network. He needs to know using this statewide health information exchange if his patients showed up for the visit at the social worker's office, did that patient pick up the prescription? Did the same patient retrieve the food from the food bank? Did the patient purchase the air mattress and fan from the store? He needs to be able to see the full picture of his patient in one system. His EHR.

One of the biggest obstacles to sharing this data is the ability to maintain HIPAA privacy while linking patients to the social services they need. I do believe this can be addressed. We need to remove the guesswork out of privacy protections by having clear guidelines and coverage for this pediatrician or other clinical providers who are becoming community, social, and digital access coordinators because they are working very hard to improve their patient's health outcomes.

We also need to consider a food bank. The local women, infant, and children's office is giving out vouchers for diapers or formula. The Goodwill store, home health, long-term care. The likelihood of these organizations having advanced systems that can contribute data in the format necessary, that likelihood is very low. Yet information from these organizations is vitally important to understand the patient's healthcare journey.

As a statewide health information exchange, we are challenged with receiving data from numerous disparate sources and our job is to receive data, transform the data into industry-recognized formats and fields, and then try to make it make sense for providers and other healthcare stakeholders. We certainly as an HIE appreciate the opportunity to be recognized as the place for health data and information but we are struggling to find ways to handle the dramatic growth in data input and output requests. Increased data disparate data sources include mobile testing and vaccination sites, urgent care, non-traditional healthcare settings, state agencies, clinics, pharmacies, community, and social care organizations. HIEs, we have to work now with data coming from patient monitoring tools, telehealth visits, wellness trackers.

We face competition from non-healthcare industry giants for storing patient data. And to top it off, healthcare data not originated in the physician practice is still not widely accepted by providers. For example, what is the definition of usable patient data from an Apple Watch? More data sources increased a need for better patient matching, creates more challenging interoperability, raises more questions regarding data ownership and governance, data accuracy, and completeness, and increases problems with data flow and security. These are topics that I am aware that this committee is currently focusing on solving. But even with all of this increased input of data, there are still large segments of pertinent health information missing in the longitudinal record. Data missing from underserved and underrepresented communities of patients and providers. There is still a large percentage of patients who lack appropriate access to healthcare services. They lack technology access, and they lack internet access.

Healthcare has become inseparable from technology. We made it where patients can no longer participate in the healthcare experience without access to technology. So, finding out if a patient has access to technology is now necessary to determine their ability to be included in the healthcare experience. We call these digital determinants of health. This digital divide that we see requires the focus on digital inclusion. Health disparities will continue to increase without the intentional focus on digital inclusion and equity. I am asking for a review of the current definitions of health equity. The current definitions of health equity must include both social determinants of health and digital determinants of health: finding out whether or not a patient has access to technology.

I would like to challenge this committee to help us ensure that the funding and focus on health equity and digital access to systems does not decrease post-COVID. And thinking of that, our rural pediatrician struggling to best serve the needs of his community, I ask for standards, privacy protection, and ways to capture and share this data. These seem like small asks to me for very big problems affecting a large number of Americans. Thank you for your time today and your consideration of my concerns.

Denise Webb
Thank you, Denise, and we now have Dr. Dominic Mack.

Dominic Mack
Thank you. Thank you for the invitation. And glad to be on this distinguished panel and thank you all for attending this session today. Well, I want to build upon what Denise stated. My colleague here in Georgia. We worked together for years, and I am actually on the board of the Georgia Health Information Network. But I am just going to slice it a little different way. My title is digital health and primary care and communities, but I have another title. The promise to the small practitioner. If you remember, as the smaller practices and the practitioners and Denise spoke about, I am not going to say his name and I do not know if he permitted to use his name but the pediatrician, she spoke about actually started in a small practice. He has a group practice, but he takes the small practice approach. Let us think about this promise to the small practice and what the small practitioners thought about when we first talked about meaningful use, high-tech act, and how we are going to enable those practices to compete. Next slide, please.

First of all, Dominic Mack, I am a Professor of Family Medicine in Morehouse School of Medicine, Director of the National Center for Primary Care. We do a lot of work around health policy, research, substance use disorders, prevention, and treatment. But also, around digital health. We have been involved. We led the regional extension center initiative in the state of Georgia. We are now the national COVID-19 resiliency network and have been part of the QPP program, so we have done a lot to enable practices and strengthen the primary care health system. That is our goal as a National Center for Primary Care. Next slide. So let us talk about the state of primary care. Next slide.

You know, AMA in May 2021, as you see the title, recent changes to the physician practice arrangements, private practices dropped to less than 50% of physicians in 2020. Next slide. I learned to use this slide and you cannot look at just one data point to tell the whole story. You cannot see everything but in 2009 when the meaning of use came about across the United States, we had almost a million hospital beds, 951,000. And we talked about the move from tertiary care, hospital-based care to outpatient care, more ambulatory remote care.

So, if you look at the slide, by the year 2016, 96% of electronic health record practices had adopted electronic health records, about 96% of the practices at some level of functionality and we are still hovering around 900,000 beds at that point. If you look at 2019, we are still around 919,000 beds. I do not have the figures for today, but if you look at the way hospitals are continuing to add additional hospitals, rurally and in urban settings, we still have not been able to have that shift where we have remote, some of the wearable devices, the remote monitoring that we thought would free up hospital beds and become ambulatory. The enabling of technology that would make the smaller practices more competitive so we could do more within the community has not occurred as we thought it was going to occur under the high-tech act. Next slide.

What this talks about is among the various specialties and you see circled in green the primary care specialty is most notable for having private practices. And I just use pediatrics, internal medicine, and family medicine. We know there are other primary care providers. But if you see the green that circled the small percentages of practice in 2020 among primary care providers that are now solo practices. Next slide. This shows that and this was all done in the AMA report from 2021, fewer than five practices in 2012, there were 40% of practices and now it's gone to 33%. 50+ physician practices have gone from 12.2% to 17.2%. Next slide.

When you look at the age difference, and of course, we train physicians at Morehouse School of Medicine, but this gives you an indication of where new providers and health professionals are going. You see at the top, for those physicians under the age of 40, 40.9% in practices with 10 or fewer. For us my generation, 55 and older, 61.4% of us are in those types of practices. And if you look at practice ownership and wholly-owned by physician practices, you look at my age group, it is about 55% which you know my age group then practices are older than me is dwindling as far as the practitioners out there. But the growing physician workforce that is coming about, this is just a summation of they are not going into the small practices and then they are not going into provider-owned practices. They are going into more hospital-based practices and for-profit organizations, employee practices, et cetera. Next slide. So let us talk about some of the work we did around digital health and how digital health is being used today. Next slide.

So, we have done some studies. We have done studies to show that disparities in primary care, HR adoptions providers, and smaller practices who have higher Medicaid and Medicare populations tend to adopt electronic health records at a slower rate. We have seen this with telemedicine and the ability to access telemedicine according to the population. And in summation, our philosophy is that these digital health tools have to be in the hands of front-line conditions serving underserved communities. Next slide.

So, we did a digital health tools study in four states across the Southeast which you see here we asked physicians how they are using digital health, and these are mostly Medicaid and Medicare primary care physicians. Next slide. The practice predominantly was family physicians. Internists and pediatricians across the four states. Next slide. That was Georgia, Tennessee, North Carolina, and Kentucky. The majority of providers did participate in some form of quality payment program including meaningful use, macro programs, quality payment programs, patient-centered medical home. So, they were active in improving quality. Next slide.

Telemedicine utilization was pretty high, 65%. Electronic health records utilization was lower than expected but it is a survey, at 65%. But it showed that digital health tools were being used. Next slide. And during COVID there was a high utilization of telemedicine and 90% of the providers had used digital health during the pandemic and 54% said they used digital health and telemedicine for the first time. Next slide. So pretty

high satisfaction rate could be better, and it was nearly 2,000 providers in this survey. Next slide. So let us talk about some of the comments with the focus groups of these physicians. Next slide.

On was that they were happy about the technology and helped to eliminate barriers to access services, especially those transportation barriers and we had some of these comments from rural communities. Next slide. But the interoperability issue remained frustrating to not be able to access records within my home system. While someone with a similar system right across town and we cannot share information. Next slide. And then last but not least the digital divide especially when it comes to urban and rural communities not being able to access information, lack of broadband, and digital divide among those racial and ethnic communities that are disproportionately impacted. Next slide.

So, the takeaway was adoption and increase providers were generally satisfied but they thought they needed to be more engaged in the decision making of the technology on the front end. And the health equity implications are that we need improved access, the digital divide remains but disparity reduction has been limited by the implementation of the digital health technology from this particular study. Next slide. So let us talk about solutions and I will just give you our takeaway and some suggestions for ONC. Next slide. And one more time. There we go. So, you all are familiar with this. We talked about health information exchange, and we talked about health information exchanges with systems that can exchange but health information interoperability as we all know is the ability for those systems to use the information that has been exchanged. That is where providers are still finding barriers, especially if they are not in those larger practices. Next slide.

So, what we are doing is trying to make sure we get more of that contextual data. We heard all through and Denise talked about the demographic information that's needed. We heard earlier about the social determinants and how do we get the information. Well, you can have total care of the mind and body of the patient. Not just that clinical record that the physician entails but the community record, the record within the practice but also within the community and environment in which the patient dwells. The patients do not dwell in practices. They do not dwell in offices. They dwell in the community. Next slide.

We provide support. We thank it's important that we continue to support. We gave through meaningful use here on the Highbridge at the National Center for Primary Care which came out of the regional extension center and remains as many across the state. We continue to provide health information exchange that's part of the G-HEN and basic supporter for providers. We think that is important. Next slide. But we have also received additional funding for the National COVID-19 Resiliency Network. Now during COVID, we can engage communities, those disproportionately impacted communities, and provide services that link them to COVID, but this is a platform that we planned to take beyond COVID to link them to services, to healthcare, to information, education, and training around those chronic devices that impact these communities the most. And that includes the community health worker model. This is that more contextual data that needs to be integrated with the clinical data. Next slide.

Just a few slides. We do have an app you can go on and just get to the Google store or on the Apple store. Next slide. There is a resource locator you can go see the risk of COVID in your area, but also you can locate services. Next slide. And then, of course, we will use that data on the back end to develop a robust research data landscape so we can look at that information and disseminate that information that gives us the data points around the social determinants for communities. Next slide.

But basically, want to leave with this. Our approach is the PETAL approach. We believe any implementation, evaluation that you do within communities you need to prioritize their needs, engage the community in the research within the technology, and that the primary care providers said they need to be engaged early. Target together with the community those issues through developing research programs and interventions that you can put in place and then, of course, continue to learn and improve upon that. But there are four things we want to leave. These are the interoperability challenges for those providers that serve underserved communities and for the communities to access the technology. Health information exchange is in silos. If it is connected to the hospital system, it can be the greatest thing, but if you are outside of that system, there is no interconnectivity as we know. The interconnectivity between states is not robust. We need to get rid of those HIE silos.

What is the corporate responsibility having to make EHRs and other technology affordable but also highly functional for those smaller practices? As we stated, small practices have closed, and one thing is because of the costs and the difficulty in managing digital health technology. Affordability is so important and ONC needs to look at that. And then, of course, we need continued small practice support. Again, what was the promise to the small practitioner with meaningful use? We have forgotten about that. Most small practices have closed, and we are still going on and I guess we figure that is just going to be the way of healthcare in the future.

And I am going to leave you with this. I like the bigger coffee chains. I am not going to name them, but I do like the mom and pops coffee chain on the corner. What is the difference between the smaller practices and the bigger practice? Medicine and the practice of medical healthcare is an art. There are different approaches to it. And the small practitioner brings something to the table that is unique and cannot be duplicated and we cannot forget that. They need our support. Let us get them their tool kit. Next slide. Thank you very much. And I look forward to the conversation. We have to remember the culture in which we work.

Denise Webb
All right. Thank you, Dr. Mack, and now we will hear from Angela Thomas.

Angela Thomas
Thank you to the HITAC committee and the ONC for the opportunity to testify today. Thank you for all of the work you have done today to provide a robust health IT infrastructure and thank you for convening this hearing on an important topic, health equity by design. As mentioned in the introduction my name is Dr. Angela D. Thomas. I am the Vice-President for Healthcare Delivery Research at MedStar Health. It is the largest provider of healthcare in the Maryland and D.C. region. I am also the Executive Lead for a large clinical initiative that is designed to address and reduce disparities in adverse maternal and infant health outcomes in D.C. When asked what does health equity by design means to me, it is simply creating a health IT infrastructure that ensures equitable care for all and is reflective of each patient as a whole person. Today I have chosen not to have slides but to openly and honestly share five firsthand experiences that are germane to this conversation, challenges, and recommendations all of which are supported by research. These experiences fall into three categories. Data collection, data exchange, and data ethics.

Let us start with data collection. The first experience I will share is regarding our attempts to identify disparities in patient safety events. The Institute of Medicine identifies equity as one of the six domains of delivering high-quality care. To deliver equitable care, we must remove inequities, and to remove them you

must identify them in part of identifying them is to identify disparities. Our goal was to identify disparities in patient safety events by race, ethnicity, language, age, disability status, incarceration status, insurance status, sexual orientation, gender identity, and more. Our challenge came when we went to identify the data fields in the electronic health record. The most available and complete data elements were race, insurance status. and age. Even for race, the lack of heterogeneity was an issue. Many races identified as other and as a result, we had a lack of heterogeneity we needed. There were many other unknown fields, such as ethnicity and language, which limited our race analysis to Black, White and Other.

As a result of this experience, I recommend that the data fields identify all vulnerable populations and be included in the EHR in a way that is meaningful to the patient. This includes more heterogeneity of race, more meaningful representation of ethnicity, identifying language as preferred spoken language as well as preferred written language. Include fields such as disability status, incarceration status, sexual orientation, gender identity, mental health status, and more.

The second experience I will highlight is on the collection of social determinants of health. In a large clinical initiative to reduce disparities and adverse maternal or infant health outcomes, one goal is to screen for and address social determinants of health across five key time points. Pre-conception, prenatal, delivery, immediate postpartum, and 0-3 years of age. It is important to note that our initiative integrates four clinical service lines and two community partners who see some of the most vulnerable patients in the D.C.

We conducted an initial assessment on the current state of social determinants of health screening efforts at the beginning of the initiative which uncovered the following: multiple forms being used, various lengths of the forms being used, a variety of questions and question formats, some forms that were used just for social determinants of health screening and other forms that had social determinants of health questions embedded, some forms that were being used outside of the electronic health record, variability and the types of social determinants of health screened for, most had no referral mechanism in the EHR at all, none had a tracking mechanism in the EHR for the outcome of the referral. And there was very little integration to communicate social determinants of health screening across clinical settings within an organization and no iteration across organizations.

The result of this is that patients are being asked the same question in multiple ways over and over. This speaks to the lack of integration and the most vulnerable patients who often have multiple social determinants of health needs can become overwhelming, reliving the reality of the adverse circumstances multiple times can be traumatic. Also, these patients have expressed feelings of overwhelm by the number of issues that they are grappling with. Because of this experience, I recommend that there are more standard questions and sets of social determinants of health questions in the EHR. A method for generating social determinants of health referrals in the EHR, the ability to track outcomes of those referrals, the ability to communicate social determinants of health information between departments, and the ability to communicate across organizations.

The third experience I highlight speaks to the importance of integrating patients' voices in their care, including the electronic health record. In the same maternal and infant health initiative, we seek to understand why disparities exist for Black women despite education and income. We seek to uncover opportunities for the prevention of adverse outcomes along the perinatal journey before it escalates to acute maternal severe morbidity or mortality issues. We are also challenged that we must reconcile the goals with the national qualitative stories and reports and research from birthing individuals, like Serena Williams, and

many other birthing individuals of color on bias, mistreatment, disruption, and discrimination in the perinatal space.

We must also reconcile how most of their maternal morbidity events are preventable and most of those are preventable at the hands of providers and healthcare systems. In addition, we must reconcile the reports, one very recently in health affairs, that document differences in provider tone, language, and sentiment in documentation in the EHR based on patient race. As a result of this experience, I recommend that we identify ways to incorporate the voice of the patient. Especially the voice of the birthing individuals of color in the EHR. We must also find ways to automatically flag and report negative sentiment and tone in the EHR. This can assist organizations with identifying additional training and other interventions aimed at reducing bias. And finally, patients must have access to see what is said about them in their records.

The fourth experience is the topic of data exchange and highlights communication of health information across organizations. In the same maternal and infant health initiative there are three scenarios where communication was essential. The first is pre-natal care being received in a community organization yet childbirth occurring in the hospital. The second is pre-natal care being received in a community organization and specialty services occurring in the hospital. And third specialty services being delivered by hospital physicians but embedded in the community setting. Seamless communication is essential in all three scenarios.

But we experienced several challenges in delivering seamless communication. There is a limited ability in the EHR to easily communicate care information from the hospital to the community organization and vice versa. In addition, in the case of embedded services, the IT infrastructure needs were so enormous to be able to have access to the HER, and then the lack of communication between the two EHR vendors. As a result of this experience, I recommend improved EHR interoperability across vendors and better communication solutions across organizations and providers including our small community providers.

The fifth and final experience I will highlight is data ethics. As researchers, our goal is to create a set of core data ethics and governance principles that guide our use of data for research purposes. As a result of this goal, we engaged national clinical and research experts as well as members of the local community and patient representatives to inform these principles. We explained that our ultimate goal is to leverage the power of data to conduct innovative research, develop new insights, and generate scientific breakthroughs that advance the health of our communities. We underscored our ethical responsibility to protect and ensure the proper use of data for research purposes. Their feedback boiled down to three main themes. 1.) To foster and promote trust through open and honest communication with our patients and communities, 2.) The data should be used for research that has the potential to advance health, and 3.) Ensure that data sharing is ethical and meets regulatory standards.

Based on this feedback I recommend the following: On the point of trust, honesty, and communication, we must disclose how data is used and why and allow consent. In all communications, these must be accessible, simple, and easily digestible by the patient. In addition, it must be reported back to the community on the use of that data. That health IT infrastructure to support organizations generating reports to be getting back to the community on how data was used and those results. Finally, the data-sharing infrastructure should not only protect the data but should also provide the ability to collaborate across organizations large and small with equitable ease for all. Thank you again for the opportunity to share our experiences, challenges, and recommendations to the HITAC and ONC.

Denise Webb

Thank you, Angela, and now we will go to our final presenter, Andrew Hamilton.

Andrew Hamilton

Hi. Good afternoon and thank you for the invitation to present to this distinguished committee and for being able to talk with our fellow panelists about how to promote the use of health IT technology standards and policies to improve health equity. As mentioned, my name is Andrew, and I started my career as a pediatric ICU nurse in 1998. I completed my informatics training at the University of Michigan in 2001 and joined the AllianceChicago in 2004 and have been committed this entire time, 20+ years, to dedicating my professional life towards the development of solutions to promote health equity. Next slide.

AllianceChicago is one of the oldest and most-respected HRSA-funded networks. It was founded more than 25 years ago to provide services to community health centers across the United States. Throughout our time, we have built expertise in infrastructure information technology including digital health, health policy, interoperability, data analytics, practice coaching, and quality improvement. Our work links more than 72 community health centers across Illinois and 18 other states and we reach more than 4 million patients each year. The communities we serve include urban and rural populations, low-income, uninsured, racial and ethnic minor tease, LGBTQ community, refugee populations, and those experiencing homelessness. Next slide.

Our mission is simple. It is to improve individual, community, and public health through innovative collaboration. And we have done this work with a particular focus on health equity in a commitment to the reduction and elimination of health disparities. Next slide. To achieve our mission, we provide organized our work in three different business areas. In healthcare collaboration, to develop an innovative community of learners to optimize the use of health IT. In health information technology development and deploy thoughtful and leading-edge technology solutions that are meant to serve healthcare providers that reach underserved populations. And finally, through an innovative healthcare research network that increases the availability of healthcare members, services, and patients in the participation and research. Next slide.

Through our journey, we learned a lot about health equity as many of you have covered today. It is influenced a lot by policy, but also about how policy is implemented into programs and services. That medical care itself is insufficient in improving better health. That payment methods need to promote the use of social determinants of health information to improve healthcare inequity. That frameworks for integrating social care into healthcare are emerging and yet not fully understood. And finally, that health information technology standards are critical to the support of integration of social care and medical care. Next slide.

Where we hope to learn more, both collectively and with all of you, is how to use and analyze this information related to health equity to inform the design and delivery of health and social care services to be more effective. We hope that the development of new data and technology solutions not only are implemented in EHR technology but go into other health IT solutions that are increasingly prevalent in our ecosystem. We look to provide multi-sector partnerships for data sharing. While we recognize challenges and share information in and across the healthcare ecosystem, it is imperative for healthcare providers to work within the community and to begin data exchange with cross-sector partners. Related to that, we need to develop methods to create an intersectoral plan of care. This is the clear mechanism to support the impact and improvements in health equity. And finally, in healthcare provision, we need to be careful not to medicalize social determinants of health. Next slide.

As many have talked about today, we too, use the learning health system as a primary framework to organize our work. The learning health model is fitting as it allows us to import evidence-based practice standards into care delivery, evaluate outcomes of the population level, and to further form the development of new science and make adjustments to existing clinical practice guidelines, particularly relative to the under-served population. I wish to share challenges and opportunities we envision as we seek to improve our efforts around health equity, and I will learn this learning health system cycle to formulate my commentary. Next slide.

As mentioned before, our work in health equity often begins with the assessment and identification of the phase of the process. A lot of work is focused on developing methods to capture data directly from patients or to use available data from outside systems to approximate social determinant risk. We have learned though, that the time and effort necessary to gather this information far exceeds the availability of time of our care team members. We have also already begun to appreciate the collecting information on patients who present for care misses or often overlook those that are, quote-unquote, "healthy," or not engaged in healthcare services today. Although data standards, thanks particularly to the work of the Gravity Project are emerging, more is needed to codify, store, and make shareable important information that we learn have an impact on health equity and that common instruments that are unused today to collect this information typically miss behavioral, environmental, social, and structural factors that are impacting health and health outcomes. Next slide.

And sometimes it is important to look back. In 1999, the Department of Health and Human Services supported something called the Health Disparities Collaborative. It was an incredible effort in which more than 900 community health centers across every single U.S. state and territory, including Washington, D.C., participated in a novel approach to implement rapid cycle quality improvement learning collaboratives and a chronic care management model to improve health disparities. And while there were many tremendously valuable efforts from this initiative, perhaps one of the most important findings we had is that the healthcare system alone is not able to mitigate the social and economic risk to ensure the achievement of health equity. Next slide.

We along with you since learned that health disparities take on many forms and formats across the ecosystem of services and organizations that our patients work with. In 2016, the National Association of Community Health Centers and its partners developed a tool for collecting and implementing social determinants of risk screening. The protocol for responding to and assessing patients' access, risks, and experiences and preparation was developed and implemented across three partner organizations. AllianceChicago was one of its key implementation partners and learned a great deal from this effort back then. Next slide.

Specifically, we learned that while it is important to understand the social, emotional, and financial need, which is often the key aspects that are captured in current social determinants of health risk tools, physical, environmental, and behavioral factors are not necessarily equally collected and thus our understanding of the patient and family is blurry. We do not have a clear picture of the current status of health amongst our patients, families, and community members. It helped us understand the need to develop multisectoral data connections to inform an improved view of what we are hoping to achieve. Next slide. This is a cartoon drawn by my friend Dale Saunders who is a technologist that helped us, and our organization conceives of a project of collecting and combining data from multiple sources and public health and community databases. We have been experimenting with using mixed-method data collection for a

long time relative to social, economic, and behavioral risk and we hope our work in this space can inform our future. Next slide.

To illustrate an example, AllianceChicago recently developed and implemented a unique model for predicting and preventing lead risk poisoning. As many of you know, the current method in the United States requires care providers to draw a blood lead level and it is only then in we find patients who have already received toxic poisoning of lead that we instigate public health, community-based, and healthcare interventions. This slide, sorry, just go ahead and click through all of that. The purpose of our work was to inform the development of a proactive model using predictive analytics. Next slide. This predictive model included data inputs from more than 11 data sources that are organized into a single data pipeline to create a machine-learning algorithm to identify both pediatric patients and pregnant women who are at risk for exposing a child to high-risk levels of lead. Next slide.

The purpose of sharing this illustration with you today is to double down on this point about the number of data sources that were necessary to create a reasonably accurate and usable model to allow our public health teams to conduct lead risk inspections even before blood lead level assessment. As you can see here, the model included information from municipal databases such as building blueprints, household tax information, city violation records, the WIC program, and EHR systems and used across the Chicagoland region. This hopefully demonstrates that there are possibilities for using existing data that is already available to inform efforts around social and economic risk. Next slide.

To address concerns about usability, we also imported the results of this model directly into our EHR system. And with the click of the Blue Button, the provider can quickly run the analysis on an individual patient, and from the results of that analysis, order lead risk inspection even in the absence of a blood lead level. This may not seem revolutionary but as a person who has practiced in pediatric health, I can assure you we have seen numerous times in which patients have been unnecessarily exposed to lead and in an instance that was preventable. Next slide.

To further efforts regarding social determinants of health, it is critical as previously mentioned by other presenters that we develop methods for not only collecting but sharing this data. We are proud to co-invest and work with our colleagues both at **[inaudible] [04:00:49]** and AllianceChicago, two health center-controlled networks to test the FHIR IG SDOH data sharing. We look forward to sharing the results of this effort not only to share data amongst healthcare providers but across the growing ecosystem of community-based members. Next slide.

The next phase of our work involves developing a comprehensive multi-sectoral patient-informed plan of care. And the work we observed several challenges related to prioritizing the needs of patients and then organizing resources from various community-based and social care organizations to develop an effective efficient and shareable plan of care across the diverse ecosystem of providers. Next slide. Taking us back to our example of developing tools to collect data, you will see from this pilot study published here that work across our community health centers identified that patients may present with as many as 22 identified social and economic risk factors. This is particularly challenging as healthcare organizations are strapped for resources and may not have all of the capabilities to respond to identified needs. Furthermore, on average, each patient in this particular pilot study at least presented with five which means there will need to be ways to more effectively and efficiently develop an organized and comprehensive plan of care. Next slide.

As you can tell, I am a bit of a buff when it comes to the use of history. Believe it or not, the first nursing care plan that was developed in the 1930s had categories of information that seem strikingly resemblant to what we need to develop today. And this example care plan that was promoted and was in use in the 30s included metrics on family members and their current health status, socioeconomic information, housing conditions, the nationality of patients in the household, as well as social and economic health status indicators. While today's nursing care plan is grounded in the biopsychosocial assessment, it is too often episodic. I believe that is the case as well with care plans that are developed in the ambulatory care mechanism. In addition, there is confusion on how to operationalize a plan of care, particularly across an ecosystem of care providers not just within healthcare but other social and community-based provider organizations. Next slide.

We are thrilled with the work that has been done by the team at HL7 and FHIR in particular to develop a standard for an FHIR care plan resource. This is an important step forward as this plan helps us identify who is involved and what actions that individual is going to take. And while we believe this care plan is in the right direction, we know that additional context definitions and discrete data are needed to further iteration this plan to ensure a comprehensive patient informed care plan that can work across a growing ecosystem of social complex care providers, mental health providers, and others in the social care sector. Next slide.

The U.S. healthcare environment, including our colleagues in environmental health, financial housing assistance, community-based service providers, and others are not going to have the depth and level of services necessary once we begin a widespread assessment of all individuals who receive care in the United States. To scale care, it will be increasingly reliant on the use of digitally enabled technology. In addition, we are already learning about the growth of digital technologies in the consumer market. Take for example the medical device market. The wearable medical device market would have seen an increase in sales from 8 million to 27 million annually in just four years. With this growth in digital health and virtual care and remote patient monitoring technologies as we heard there is an increasing concern about the growth in the digital divide. Next slide.

While we applaud the efforts at FCC and other federal agencies to make broadband services more widely available, the infrastructure investment in the jobs act is not effective if people cannot use online technology in services. Digital literacy is rapidly becoming one of the most significant drivers of health inequities across the U.S. health space as indicated not only in healthcare in the COVID-19 pandemic but also in cross-sector organizations such as teaching and learning institutions and primary care education. Next slide. Digital health literacy is a critical aspect for policymakers, program service creators, and the workforce to learn and understand the development and delivery of services and tools. We need these tools to be responsive to a growing need for diversity across age, race and ethnicity, gender, sexual orientation, primary language, and other socioeconomic variables. Furthermore, it is important to create mechanisms to track digital health across those few demographic populations to inform where future investments are needed to ensure we can close the digital divide. Next slide.

To achieve the ultimate aim of precision medicine we must increase our understanding of the role of social, environmental, economic, and other factors in health and health outcomes. We must grow the scientific knowledge by which we base our implementation and intervention decisions. Big data and advanced analytics including machine learning and artificial intelligence are increasingly prevalent in healthcare and certainly provide tremendous promise toward optimizing diagnosis, treatment, and intervention. Next slide.

However, before the explosion of machine learning and AI, it was well documented that research programs in the United States significantly underrepresented racial, ethnic, and other sociodemographic groups in research. We must develop efforts and methodologies to improve the participation in underserves and underrepresented communities in research. Furthermore, we pay specific attention as was previously pointed out to the development of machine learning algorithms that can perpetuate health disparities. To achieve an equitable health system, we must intensify our efforts to increase the diversity of individuals engaged in research and evaluation. Next slide.

In summary, I will close with thoughts about our efforts around improving an equitable learning health system. First and foremost, we should expand health information technology policies and standards to increase the availability use of heterogeneous, multi-sectoral data. We should then support the development of IT to encourage the coordination of intersectoral care planning and interventions. We must think beyond traditional healthcare systems to develop methods to effectively decrease the digital divide. We must promote the development of community-based training programs and optimize the use of digital health tools which account for varied digital literacy, and finally, we must intensify efforts to improve the number of individuals engaged in research and evaluation.

I would like to close by thanking you for your time, both the HIT adviser committee and fellow panelists, and most importantly to extend my gratitude to the more than 260,000 individuals that work at more than 1,350 health centers in every U.S. state and territory. I have faith that our government and private sector leaders working together can achieve a more fair, just, and equitable community for all.

Discussion (04:09:05)

Denise Webb
Thank you, Andrew, and thank you, Dr. Hines, Dr. Mack, and Dr. Thomas. We appreciate your testimony and we have about 15 minutes for discussion. And so, I want to open up the floor for the HITAC members to engage in discussion on these topics. No hands. Any comments? Ah, Eliel, yes. Go ahead.

Eliel Oliveira
Thanks, Denise. I think we have thoughts going on in the chat that I think are important to highlight. ONC and this committee, we talk a lot about standards in data access for clinical practice. When we are talking about health equity and the collection of SDOH pieces of data, I think it becomes a little broader than just electronic medical record systems. I have seen notes about the collection of needs assessments, you know when folks come into the clinic, and I believe that needs to be happening when I have needs which can happen at any point in time in someone's life. Some of those pieces of information I know other systems are not electronic medical record systems.

So, I will give you an example, here in Austin our key problem is homelessness with the growth we experienced in the city. And to manage that effectively, we need to know when individuals are leaving the jail system so that we can coordinate and make sure they are not going to be mistreated and we need to know from our homeless coalition who is currently homeless or at risk of homelessness. They have a health HIMS system of those coalitions, and they are not going to be able to communicate with the HRs the way we do today. I think that there is an opportunity there to expand the view of how we collect and integrate systems to be able to address health equity efficiently because it is solely focused now in clinical practice.

And when individuals show up at the clinic and that is not going to help us much in effectively solving some of these challenges.

Denise Webb

I think the point was made that government, or state government in a lot of cases, holds a lot of data around social determinants of health and the services that individuals are receiving through the government programs. I spent 16 years in the Department of Health Services here in Wisconsin and most of the programs were very one-to-one focused when it came to data and systems rather than having the individual at the center where all of the systems that were serving that individual were able to share data. We made a lot of progress to move away from that one-to-one and to have more of a hub-and-spoke focus, but we have got to get the state government programs and local county programs that provide a lot of these services and work with the local community providers to pull all of this data together. That would be helpful.

Eliel Oliveira

Yeah, one last point I have, Denise, is that different communities are going to have different priorities and problems like the one I described. Austin is homelessness, Houston is food and security, and other places will have different things. There is an opportunity to think on that front as well, which problems to address first because it is a big ocean of SDOH out there.

Denise Webb

Yes. Thank you. Dr. Mack.

Dominic Mack

Yes, good comments. I just want to add, I think, for example with research, is Medicaid data. Medicaid data has a cost that most community-based organizations or grass-roots organizations cannot access that data and that is the data about underserved populations. That is just one example. All of the public databases and these private databases that we have that contain that information around those social determinants are not readily accessible to communities. Also, they are not integrative as Eliel was saying. They are not integrated with a clinical record. So, I think that goes back to the comments about the silos.

I think ONC and us in the community have to figure out a better way in lowering the cost and barriers to integrating information, but also make it available back to communities so that they can utilize the innovation, the information to improve the care of the community whether it is homelessness, et cetera. I think also to what **[inaudible] [04:15:05]** was saying, the technology. The poorest of the population, are not connected to the technology where we can track them. Especially in the behavioral health system. A lot of folks once they leave the state hospital, no one knows where they are or the correctional institution, no one knows where they are until they get back there. Between that time, they have had a lot of events that really can traumatize their health and leads to the worst healthcare. I wanted to say those comments. Thank you.

Denise Webb

Thank you. I know one of the approaches that we have taken to address this here in Wisconsin is for some of those programs to share the data with the statewide health information exchange and make it part of the longitudinal record that can be available to some of those community organizations. But we need standards. Anyone else?

Clem McDonald

This is Clem.

Denise Webb

Hi Clem.

Clem McDonald

I have not said much today, but I think your point about the health information exchanges is well taken and they have been under supported. I mean, they are a great opportunity, and some states are quite active and broadly covering, and many of them do tie into the community health centers. I would like to encourage more of that so that you get, at least in a regional area, you get good coverage of your patients. Now how much of the activity data that someone is changing status in terms of homeless or not, that may be tough. But a lot of these, many systems, community health, community centers do try to keep track of the fact that this person is or has been homeless. I think it cannot be overemphasized. It is already there, but with a little extra boost, they could do a lot more.

Denise Webb

Great. Any other comments or discussion? If there are no other comments, I want to, again, thank the panel of presenters, appreciate it. And we are going to have a break and return at 3:00 p.m. ET and I will turn it over to my colleague to moderate the next panel at that time.

Aaron Miri

Great. See you then.

[Break]

Mike Berry

And hello, everyone. Welcome back from a short break. We are resuming the March HITAC meeting and Health Equity by Design Hearing. And I will now turn it over to Aaron to get us started.

Content and Exchange of Data, Part 2 (04:18:16)

Aaron Miri

Thank you. Appreciate it, Mike. All right, everybody. We had an exciting, exciting morning and early afternoon. We are going to end it strong here with another great panel. Continuing the discussion, we just had, we have some very distinguished panelists here. First up is Janet Campbell, Vice-President Research and Development for, you know, that EHR company, little guys up north. No, I am kidding. Epic systems. Great, great EHR. Second is Dr. Robert Murry, Chief Medical Officer from Nextgen, another great organization there. Jaffer Traish. Chief Operating Officer from findhelp. And Carlos Uriarte Vice-President Regulatory Counsel and Read Holman, Policy Director at Unite us. We will hear from Dr. Trenor Williams, the CEO, and co-founder of Socially Determined and we are going to go from there. So, up first is Janet, you are up.

Janet Campbell

Thanks so much. Good afternoon, everyone. My name is Janet Campbell I am a software developer and Vice-President of R&D Relations for Epic, and I am very thankful for this opportunity to provide Epic's perspective on the opportunities that we all have to better leverage information technology to both identify,

monitor, and ultimately treat the real, very real disparities that currently exist within the nation's healthcare system.

Our testimony today is informed by over 40 years of experience developing EHR technology. Our software is deployed in every state in the country, including at numerous federally qualified health centers, and throughout healthcare settings, representing both more traditional fee-for-service-based reimbursement models to full at-risk arrangements, and everything in between. Our organizations provide everything from street medicine to concierge care and moreover, our software is used internationally, including in countries such as Finland, where the social care system is administered using the same EHR as the healthcare system.

Based on our experiences in these varied settings, we would like to propose the following priorities for identifying and treating the disparities of care and outcomes in medicine and healthcare today. Understanding disparities in outcomes first relies on having accurate and complete data to identify patients. The thing is collection of race, ethnicity, and language information is supported in most certified EHRs today. And yet, we still face many challenges. Data collection rates remain very low. Perhaps due to patient resistance or lack of organizational commitment, many organizations lack accurate data about their patients which makes identifying disparities difficult if not impossible. I would like to recognize one organization that uses Epic, UC San Diego Health increased their collection of race, ethnicity, and language, going from having that data on less than one-third of their patients to 94% of their patients. They achieved that through a combination of staff training, patient communication and outreach, and workflow redesign.

UCSD proves that increasing collection rates is possible, but it may take more than just technology to achieve it. HHS, as well as professional societies, should collect best practices from organizations like UCSD and model and encourage them both more broadly so that others can replicate that success. Additionally, standards for representing race, ethnicity, and language are variable which can introduce confusion for organizations who are attempting to capture and summarize this data for given programs. Race and ethnicity are represented at different levels of granularity and through different code sets and there exists little guidance or standardization on how to roll up those granular representations to report. I would like to recognize ONC's initial work to survey the landscape of code sets and the capture of different strategies across the HRs. We encourage additional efforts to reduce code set irrigation across programs and provide best practices for balancing granularities in this data with appropriate roll-up strategies.

When race, ethnicity, and language are consistently collected and represented in EHRs we then have the opportunity to identify disparities. Existing electronic clinical quality measures, which are already widely in use to measure the extent it which providers adhere to clinical best practices of care, are today stratified by race and ethnicity. We recommend establishing and publishing benchmarks that consider these stratifications as well as others such as preferred language or sexual orientation and including them in more public reporting about overall program success. Such transparency will allow CMS, Congress, and other policymakers to track the extent to which current programs are truly benefiting all individuals and more precisely, identify opportunities for improvement. These three interventions while seemingly small can begin implementation today and they represent the most immediate opportunity for identifying disparities in care.

But beyond that race, ethnicity, and language data, which can describe patient demographics in broad strokes, more important to a holistic understanding of the health is information about their social determinants. While many organizations regularly assess patients for concerns about lack of access or

such as lack of access to transportation, exposure to environmental dangers, or risk of past or current trauma, representing this data in a standard and the uniform way is not yet mature. We are encouraged by the inclusion of SDOH data into USCDI version 2 and the proposed representation of the data and CDA documents and FHIR resources. However, the industry will need much more experience implementing standards in small pilots before moving to widespread adoption.

Exchanging this information in a meaningful way will require much more alignment among stakeholders about which social domain should be assessed and what screeners are appropriate for assessing each domain. For example, is a housing insecurity risk score of seven worrisome? If the community cannot align on standardized screening assessments, ideally made available without licensing restraint, each organization will need to map their customized assessments to some sort of standard risk determination and that is an onerous exercise that could introduce numerous complexity and delay implementation. The good news these technical difficulties or these technical challenges are solvable even though progress may feel slow.

We encourage HHS to support and work with existing efforts such as HL7's Gravity Project which was designed to align data concepts so that standardization and exchange of data will be possible. Assessing social needs in patients is only the beginning. To address these needs, organizations are dependent on a patchwork of social programs and agencies. Some programs are well funded and technologically sophisticated. For example, Trinity Health, they administer a diabetes prevention program through their EHR that includes health coaching at the local YMCA and healthy food through Trinity's farm share and using both patient-facing technology, as well as portals for the community partners, Trinity is made more than 450 healthy food deliveries to 50 households per week.

However, the majority of work to address the social needs of Americans still relies heavily on community-based organizations with little to no interoperable technology and in some cases even limited connectivity. In many ways, the social care landscape of today resembles the healthcare landscape of 15 years ago and has an opportunity to learn from successes and challenges that stemmed from the high-tech act and to apply those learnings to modernizing the fabric of our social support network. We should incentivize the adoption of interoperable technology by community-based organizations. We could develop and establish curricula to help those organizations hire the staff that has the poor competencies that are needed for more a connected environment.

We could do that or help the process by establishing regional entities that can help agencies understand and choose among technological options and aid in their implementation. We should finalize the HIPAA coordinated care NPRM that was issued in 2021 to enable increased operability among all stakeholders including more sensitive entities. We need to reduce individual state-by-state variation and privacy laws that might impede interoperable exchange. And finally, we can embrace the existing work that has already been done through TEPCA to prioritize future adoption of social care use cases as standards mature and as trading partners come online.

Certified EHRs and healthcare organizations hoe use them will play a crucial role in strengthening how our country cares for all who call it home and all of us in these virtual rooms together have spent time and money and energy building the existing healthcare technology ecosystem into what it is today. Now it is time to fold social care into that technological infrastructure, not as a separate or standalone entity, but as

one that can interoperate freely and with ease. We look forward to continuing to work with you on this most important issue. Thank you very much.

Aaron Miri

All right, thank you very much, Janet. Excellent, excellent presentation. All right. Next up we have Dr. Robert Murry from Nextgen.

Robert Murry

Thank you, Aaron. Thanks to the high-tech committee for both having me present today as well as to the ONC and the committee for all of the work you are doing. It is a lot of volunteer time and we really do appreciate it because there is a lot of good coming out of the work so far. Next slide, please. So I am Dr. Bob Murry. I am a practicing family physician, but I am also the Chief Medical Officer for Nextgen Healthcare. So, Nextgen Healthcare is an EHR vendor, as well as an HIE vendor, and we serve a large number of ambulatory practices in the U.S. including a large number of community health centers. I practice in New Jersey, and I have board certification of both family medicine and clinical informatics and just years of experience both with the implementation of the EHR systems and other surrounding health IT. Next slide.

So, we talked about health equity all day and we did hear a couple of different definitions I like what we heard, and I also like this one from the CDC. Health equity is when every person has the opportunity to obtain her or his full health potential and no one is disadvantaged from achieving this potential because of social positions or other socially determined circumstances. Next slide. And as a practicing physician and a health IT executive, it is clear that the effects of social determinants of health-on-health equity are obvious. Right? And unfortunately, it is also clear to me that these are not easily fixed in the exam room. I think we have not said it explicitly, but this group believes that health equity and social determinants are going to be addressed at population levels, at cohort levels, in addition to the level of the individual patients and patient care. And there is a lot of these things we cannot fix. There are a lot of these things that have nothing to do with health information technology but trying to focus today on what the ONC can do and what the HITAC committee can recommend, I think there are probably five areas and most of what I am going to say today you heard from the other panelists who have done a fabulous job. It has been a great day.

So, a lot of information, emphasis on health data collection which I agree with, and we will get into more detail. But the next two are the power horses of what we will do to address health equity. We need to get enough data that we can analyze it and that analysis needs to be actionable. We heard examples of this throughout the day. I will go over a couple of others. The other is to realize that the addressing of health equity is going to be a team sport. Just like medicine is a team sport and that team needs to be able to communicate with each other and the interoperability work and the exchange work of data that ONC has done so far will be so important. I am also going to argue that health information exchanges, HIEs, could play and they are playing a great role in this problem. And then finally I am going to advocate to the HASF level more than the ONC level that this access to healthcare we have heard about several times today is absolutely a critical part of the problem. Next slide.

You cannot manage what you cannot measure, and we heard many times today that we are making progress in terms of the types of data that we are collecting that I will call health equity data. It is race, ethnicity, language, **[inaudible] [04:31:25]** social determinants of health and we applaud USCDI v1 and now the v2 and v3. We applaud the Gravity Project, but I do think the high-tech in the ONC can help as those standards develop by trying to focus on the standardization of data that is going to be involved in

either the analysis of health equity or in the mitigation of some of those concerns. There are all kinds of things about people that we may want to know but there is a burden that comes with the collection of that data and so I do think that ONC can help by ensuring that the standards that are put out there are certainly the ones that are required are the ones that will require the biggest impact.

And similarly, as a practicing physician, I think that Steven Lane said it earlier, either in the presentation or the chat, we have to balance this benefit and the burden. So, every time that we introduce a new quality measure, a health equity quality measure even which are desperately needed, I agree, we need to take something else off of the provider's plate, off of the health organization's plate. We cannot continue to just add to the work that the health organization must be done because we all must also realize we are in an environment where physician burnout and healthcare provider burnout, particularly due to COVID, but even due to EHRs and other health IT. That burnout will hurt us in a big way if things continue as they are.

Finally, I will reiterate some points that came out in the chat with the most recent presentation. So social determinants of health and a lot of the data that is related to heal equity are some of the most private data, the data that people would not want others to see. And yet we do not have a framework for patients to be able to explicitly give consent for which parts of that data they feel comfortable sharing and with who. And how does that consent travel with the data as an inner exchange with other healthcare organizations, right? And we all believe in information sharing, which I will define as maybe the opposite of information blocking, but there is going to be a backlash against information sharing if we do not address this privacy issue and this control of data issue. There are several excellent ways to think about that. This is, in my opinion, straight up HITAC and ONC's alley. Next slide.

Once we have collected the data, we will analyze it and I would argue this kind of data collection, data analysis, action on that analysis, is the workhorse of mitigating health inequities. So, we need to realize that there is a huge number of actions that can be taken on this data. We can do patient outreach. We can plan services by geographic need. We can compare performance. We can do quality **[inaudible] [04:34:38]** We can do referrals and care management. All of these actions need to be supported by the tools that we have for both data collection and analysis. And so, what I would love to see and ONC would help push this at the HHS level, but I would love to see health equity kind of key performance indicators.

Health equity is an enormously broad topic. There are all kinds of equities we can do. Are we going to talk about vaccine rates by race? Are we going to talk about childhood diabetes by income or geography? But at the national level, similar to healthy people 2020, I would argue we need a policy for what are the most important initial health equity KPIs that we should be addressing because we, as a health IT industry and healthcare industry, can start to build tools and communications and data standards around those objectives. So, I would argue let us try to have HHS and Congress and the administration set those priorities. ONC then help define the way we will measure that so we can maybe all get on the same page.

So similarly with the data analysis, we have heard a couple of times about the great work that state-level Medicaid programs or behavioral health programs can do but the reporting standards for those programs, you have seen one state, and you have seen one state. It adds a significant kind of cost into the system the fact that you cannot use the same reporting mechanisms in all states for many of those programs. Some are thinking about registries. We have 54 immunization registries for 50 states. That does not include the territories. And all of them have different standards. So, what we are doing here is we are just adding cost into the system. We are adding complexity and discouraging innovative new entries. We are not making

the system easy to use at a nationwide level and therefore easy to measure and easy to coordinate at a level. If ever there was a role for the Office of the National Coordinator, I would like to advocate for the coordination at the nationwide level of these kinds of reporting and registry standards that are happening at the state-by-state level now.

Finally, I was going to tell you a story about a population health risk calculator tool that was found to have a bias in it and then we heard the lead author of that study earlier today so thanks to the committee for putting that together. There is a real need a knowledge that these algorithms are rife with bias and that bias affects people's health and care and distribution of resources. And we need to recognize that for the folks that are going to be developing these algorithms, those need to be built in that the fact that you are going to study its biases and just like the ONC has made it a requirement that you list the reference and the funding sources of any kind of clinical decision support that is used within an EHR, you should also have to study and make transparent the biases in those tools because many of them are not free. Either the providers or the vendors are paying for them. Next slide.

So, there have been great strides in the exchange of data in interoperability here. And just as a clinician we hear all kinds of definitions of interoperability. We know the 21st century cures definition of that. I would like to use this one that came from CLASS, the ratings and reporting agency a couple of years ago. It is not even their newest one. But as a physician, what I want interoperability to do is I want to know as I am seeing a patient, is there data out there somewhere? I want to be able to get that data. Ideally automatically. I want to be able to incorporate that data into my system and finally, I care if that data is going to affect care delivery. And the other piece about interoperability, we need to keep in mind that interoperability has to be vendor agnostic. Anybody that will define interoperability as only between my system and my system, and then advertise or invest based on that definition has an agenda. Vendor agnostic interoperability is in line with the way that ONC thinks about things and defines things, so we certainly applaud that.

So in terms of suggestions like many others like these social service agencies and providers that are going to be at the heart of addressing health inequity, do not have access in many cases to the interoperability tool and there is a real opportunity to try to make low-cost tools and incent folks to use them so they can be at the receiving end of all of this great data we are collecting and also coordinate with the healthcare providers because it is going to take both of us to address a lot of these concerns. I think we would be remiss here not to realize that nationwide patient identifiers would be helpful in this regard. Not having it leads to cost, inefficiency in terms of time, medical error, and anything that adds cost to the system or adds medical errors, it has been shown it tends to hit historically disadvantaged groups harder. So, we are making our health equity problem worse by not solving that.

I found it fascinating that actually, Andrew Hamilton earlier in the previous presentation argued for the need for a better care plan. So, the HL7 care plan is required for ONC certification. It is very structured and not necessarily the way that clinicians think about the care plans. I would love to see a more clinician-friendly interoperable care plan. You can share easily everyone can update it. But I think we need more clinical input into the vehicle that could play a central role in coordinating the efforts of these agencies as they are talking to one another and all trying to coordinate services for the patient. Next slide.

So, I would like to make a pitch here that HIEs, Health Information Exchanges, can play a unique role I think in addressing the health equity problems in the country. So, they are maybe not even designed this way but are starting to act as data collectors that are connecting, that are starting to act as utilities that are

connecting data collectors, typically healthcare organizations with data consumers like utility. And like a network, there is a network effect that the value of the network, the value of the HIE increases the more connections it has and so they are one of the few people in the system that incentivize to connect people and they also incentivize not to charge a lot for their connection to the HIE.

And I think because of that, in addition to their historic mission, I think they are very well positioned to help with this problem of trying to extend the challenge or the addressing of the challenge of health equity beyond just healthcare organizations and individual practices but into the social services organizations and communities where we all know it needs to be solved. If the ONC and HITAC share the view of the HIE, there are several ways they can support that vision but once again an obvious one, in particular, is that many HIEs are subject to federal and state regulation and if they try to cross state lines that gets problematic. There is room here for a nationwide type of approach for standards and regulations. Next slide.

My final set of points would just be around how important access has become in addressing health equity and many of us speakers have said this, and it is not strictly in the purview of ONC, we are talking HHS and Congress and other agencies here. And of course, I think, access to healthcare itself needs to be addressed, but access to technology has become so critical in how we can have a realistic way of addressing health inequities. So, for instance, virtual care with COVID, obviously exploded very quickly because there was payment parity, and we think that parity should continue but it is important as we start to regulate virtual care that it be designed or encouraged to increase access for the disadvantaged as opposed to just convenience for the privileged. Two ways can go. Those are not necessarily mutually exclusive, but you can see how nudges one way or the other can push the system may be in a way we do not want it to go.

Finally, the future is going to involve a lot of care that is not happening in traditional offices and clinics. It is either going to be in the home or other sites of care and ONC and the other agencies need to encourage that innovation, encourage the data interoperability that can enable it, and realize that it takes a village to take care of each of us. Similarly, access to the internet itself to broadband and devices is so key. We have many examples of this where our clients need to provide devices to people, maybe migrant workers, because those workers just do not trust the downloading of apps on their phone because they think they will get reported to immigration services for instance, but they will take an anonymous laptop and do a virtual visit with that. Or we have got folks providing street care to the homeless. That is very difficult if they literally cannot get a cell phone signal where those folks are. So, broadband access nationwide is going to be critical to addressing health inequities.

And finally, just a broad kind of call and Dr. Mack alluded to this as well that physicians want to practice in underserved areas and populations, many of them do. But it becomes difficult if they cannot stay independent or they cannot be profitable doing that so again it is a very broad governmental policy level we would love to see some encouragement of that independent physician access particularly when they are part of the answer for health equity. Last slide.

So, I love the concept of designing a healthcare system that has equity. The way I would like to picture it is software, modern software has tools that are built into it, and they can monitor how users use the system and that can be used for changes to the system. That is how the health system needs to work. We need to be able to capture data in the normal process of delivering care, with no extra steps, and we have to do that with a lot of respect to privacy. We need to get some kind of direction, policy direction for which are the

most important KPIs for the future. I think the future will have an easy exchange of data between all kinds of healthcare organizations. And we will need to expand access and have it which is going to help lower the barriers to care and give us an environment where we can have equitable care for all, and social determinants will not be a primary factor in health outcomes. The last slide is a thank you slide, and I will turn it back to you, Aaron. Thank you.

Aaron Miri
Absolutely. Great job. Thank you very much for that. So, next up we have Jaffer Traish. Did I say your name correctly?

Jaffer Traish
Yes. Jaffer Traish.

Aaron Miri
Jaffer. Thank you very much. There you go.

Jaffer Traish
Of course. Next slide. Thank you. Thank you to the Office of the National Coordinator for the opportunity to provide this testimony and I thank you to the distinguished co-chairs and members of the committee for your leadership and relentless efforts to support the health and wellness of all people. I am humbled to contribute to the national dialogue to advance health equity and welcome the responsibility to deliver to you key learnings in the voice of families and communities that we serve. My name, as I said, is Jaffer Traish. Our company is called findhelp. formerly Aunt Bertha. Without diving into my background, I was fortunate to have two parents. Though they both grew up in poverty, they fought to help others, one through health research and the other through social work. And they offered an unapologetic perspective on community-centered service. Next slide.

To people and organizations that help others, findhelp is aiming to be the modern safety net that brings dignity and speed to the process of getting help because of an open community organization network that can help all people know what social services they are eligible for and if an organization can pay for that service on their behalf while protecting the privacy of the individual. Our mission is to connect all people in need in the programs that serve them with dignity and ease. Health equity by design is a core part of our mission and health equity drives our product principles for the technology and network we build. I want to focus testimony on health equity as it relates specifically to three social care principles. Next slide.

Today is the first time we are sharing the following sober statistics on the record publicly. Each week more than 350,000 people look for help through the network including food, housing, transportation, and healthcare, and connect to programs. Each month more than 150,000 electronic social care referrals are sent across the network. And more than 9.5 million people in the U.S. have used this network to find help. Next slide. Through digitizing the nationwide supply of non-profits and reduced-cost services, we are aiming to democratize how people can find and apply for services. We are a public benefit organization and are proud to have earned the trust of 400 large organizations, including seven of this committee's members organizations. Next slide.

Healthcare is moving quickly to adopt social care. We know this in the network, and these are just some numbers of those who adopted social care to improve the health equity of their work. Next slide. When we

think about health equity and the aims of inclusion, equitable outcomes, access, and affordability, we think as an organization back to 1964. The Economic Opportunity Act by President Johnson paved the way for neighborhood health centers including in **[inaudible] [04:49:27]** in Mississippi and Columbia Point in Boston and now, of course, we know 1.400 FQACs are serving 30 million people with medical, social, and behavioral needs. And we must remember that health equity cannot be achieved without working to eliminate poverty and the root cause disparities that we talked about today. Next slide.

I want to focus some testimony on two core principles of equity and social care and one core principle of working with the government. Consumer-directed privacy, equal access to an inclusive network, and government partnership through capacity-building standards, and of course, innovation demonstrations. Next slide. On privacy, many people are aware of the privacy protections that guide the handling and storage of medical information under HIPAA. It is regulated. There are penalties for misuse of what is considered protected information. Social care, of course, can be created, shared, and used entirely outside of this regulation. It crosses sectors, it can originate in non-covered spaces, and then in the absence of misguidance, some technology companies today are taking advantage of the lack of a sound policy framework and the legal repercussions related to this data sharing. Next slide.

We must remember there is a stigma that comes with needing social services and with whom we share the sensitive information. When I am ready to receive help, we must respect the sensitivity to not lose trust with our patients, constituents, students, and not lose them in the care journey. Many people needing these services are newly unemployed, survivors of trauma including incest, ex-offenders trying to re-enter society, and parents helping their struggling teenagers. People expect this deeply personal information, which is housed potentially in an EHR or closed-loop referral system, to only be visible to organizations and people they choose transparently. We have made it our mission to offer the most appropriate safeguards and built important and necessary consumer-directed privacy approaches into the technology to support this equity. Next slide.

We support self-navigated referrals where the person can self-find and refer with complete privacy. This is specifically useful for circumstances where someone is not yet ready to share or ask for that help. This is a kiosk in New York City. Next slide. We do not, I repeat, we do not automatically share those referrals to customers or other organizations because they are private. Customers and non-profits might request access to that private history and that person has the option to grant that access. Next slide. Here is an example of the individual approving that access. Next slide. This is very similar to how a medical patient if you self-pay for a procedure that information does not automatically go anywhere like to an insurance provider or affiliates unless you choose. Now after the person has approved, the information is available to that care coordinator. Next slide.

We track the consent on each instance of the referral intentionally, so we know the appropriate parties to that referral. The community organization, the person, and the helper. And this allows any technology to bring transparency and were to share that information to support the person in need. Next slide. The person in need can add or remove the organization's access to that private referral history at any time. Relationships change, people move. This transparency is essential. Next slide. We respect cross-sector care coordination agreements when they are in place, and we are trying to build the technology for that longitudinal referral history to be viewed across organizations with the right privacy controls. Next slide.

It is important to recognize the potential harmful alternatives that are out there in the market today. One-time all-in consent models provide open lookup of a person to any organization in a network. Imagine if you signed one consent form to have all of your information put into a database and just to receive that food referral. But with one lookup, more than 120 non-profits can view your financial, social, and medical information in its entirety. This is not a hypothetical example. This is the exact language of the consent in one of these models. I will not read it, but it essentially says this information may be re-disclosed and no longer protected. In the words of one healthcare professional on a national committee, holy mackerel! While an open access consent model might allow for convenience, we believe that the lack of clear safeguards to protect consumers' HIPAA-adjacent data will continue to have a chilling effect on equitable access, trust, and use of these social services through EHR or closed-loop referral management systems and networks. Next slide.

Through technology, we support anonymous search and connections to programs. Some vendors, one example to the right, might require submission of all of your demographic and identifying data just to perform that search or connection. Next slide. New Hampshire, Connecticut, Rhode Island already today are leading the way on this issue by drafting and considering legislation in a bipartisan manner to ensure proper and sound privacy controls when sensitive information is shared with social service agencies. Next slide. We are working to serve millions of people using a model that includes this informed consent at the time of referral. This example is what is happening in North Carolina. It has not hindered care coordination and most importantly, it enables a solution that respects the right to privacy. Equity through privacy. Next slide. On access and holistic networks put simply people deserve to know their options for receiving help. The full opportunity of programs that might serve me in my neighborhood 22 organizations offer emergency food. But offering a holistic network, I can find organizations that speak my preferred language or an organization that understands veteran trauma. Next slide.

We recommend this equity by design approach to the network because we have chosen to be accountable to the network quality through human curation and partnerships. These are some of the intentional program additions we have undertaken through our staff. Dental care programs in states that don't have adult preventive care. Indian health service programs, centers for independent living programs. 3,000 COVID-19-specific support programs and many, many more. By investing in a holistic network, we aim to be as inclusive as possible in the types of services that people can find. And those that work in the network today can create focused or preferred networks maintaining the best of both worlds. Next slide.

This is so important here. We recently reviewed our data to assess if healthcare, of which we work with 160 health systems, is helping people connect the programs serving all of one's needs. It is likely not surprising to those on this committee that 94% of referrals were limited to housing, food, and medical care. Goods, legal, education, work, transit represented only 6% of what healthcare was helping people with. Regardless of this industry bias, we know that people receive outside of the healthcare ecosystem. Next slide. Schools, libraries, kiosks in New York City, by offering a holistic network and not one catering to industry incentives, we are bringing equity to the process of finding help and this represents the diversity of needs among the community. This happens to be Pennsylvania. Next slide.

On government partnership. We believe and support the government's influence on modernizing the social safety net We also believe the government can be mindful of health equity and the vehicles used to disperse funds, create certifications, establish standards, and prevent monopolistic behavior. One of the most equitable approaches to communities is applying for funding directly to capacity building of effective non-

profit organizations and by providing funds directly to the source we remove industry bias, eligibility bias, and maximize the resource value going into the hands of those in need. And through technology, we can offer needs-based data to philanthropy to aid in their funding direction. Of course, we applaud the efforts to expand USCDI so the specifications can encourage, regulate, and certificate if the technology like ours complies with interoperability. We are live with this by directional interoperability not only with source systems but CBO systems, non-profits as well. Next slide.

We support CMI demonstrations, 11-15 waivers, state plan amendments that explore improvement in healthcare outcomes through value-based or contracted non-profit networks and support these contracted networks including in states like Massachusetts and California and we believe these are important pilots in demonstrations, but they may not support all people in need in a given region. Next slide. We believe in the future there may be a role for ONC to certify FHIR based interoperable vendors that can demonstrate accurate state and federal reporting for these funded programs. We were certified for the AHC grant model and we think that is very important. We also believe in the technology supporting tracking for non-profits, so they don't become a back-office system and challenge their ability to serve. Next slide. We must be mindful of the lessons of the past that have been brought up by this committee even today. In 2015 when Dr. Chang chaired the policy committee, the committee noted already advanced health models are responding to the challenge by granting community organizations access to a single platform instead of interoperability. Next slide.

This point could not be more salient than today where we are seeing some states attempt to mandate one platform to be used by thousands of non-profit organizations instead of leveling the field for innovations through standards and reporting requirements and this has allowed some technology vendors to go as far to demand or require exclusivity in contracts with community organizations. This is close to state-sponsored monopolization that will not advance the goals of health equity. Next slide.

At CMS and ONC become more involved in promoting social determinant efforts, there is an opportunity to share guidance, letters, and education across the states. We must be careful not to inadvertently fund technology or a monopolistic approach that fails to offer health equity by design in serving all people. So, in closing, we are all seekers at some point in our lives giving up our privacy should not be a contingency of getting help. Being privileged to have a healthcare entry point to a social worker should not be a contingency of getting help. And government can ensure that technology is not forcing exclusivity on communities' use on innovation siloing data and adoption. We will continue to invest in health equity by design and continue to offer findhelp.org to the nation with great respect and appreciation for this committee's time and attention. Thank you.

Aaron Miri
Thank you very much. Appreciate that. Excellent comments there. All righty. Next up, we have Carlos and Read.

Read Holman
Hello. Read Holman, Policy Director here with Unite Us with my colleague. We are going to tag-team this and we just appreciate the time and opportunity here to present, alongside just esteemed colleagues. We are all here trying to advance the same agenda. And I am going to speak a little bit about Unite us and how we think about equity by design. Unite us is a technology company with a mission of connecting health and social care and certainly agree with one of the earlier panelists here that were highlighting the importance

of thinking about work in the clinical space and as the healthcare system is, thanks to the Affordable Care Act and other transformational policies that have been put in place at the federal and state levels, as the healthcare system moves towards deeper integration with the community. As the community thinks about deeper integrations with the healthcare system, how do we bring lessons learned from the integrations from strictly the clinical side into the social care side and certainly as we think about bringing these two worlds together? Next slide.

Pretty commonly cited statistic and I do not present this as educational material but simply as an anchor point for this conversation. I think it is a shared recognition here that the drive of health equity begins with the recognition of the fact that 80% of health happens in the community. 20% of health outcomes are driven by clinical factors and those are important, but 80% are non-clinical factors and things such as housing, transportation, food services, et cetera. The challenge has always been about the wide gap that exists between the worlds of clinical care and social care and Unite us has a mission of helping to bring together both of those worlds in the form of cultivating communities and cultivating networks of organizations that agree to operate in a new and transformational way. Next slide, please.

And we do this through, we call an end-to-end solution. We have a suite of tools and services that are meant to support the client and their care journey from the clinical world. I had, even from my privileged life experience, have had to navigate my care on the clinical side. It is a really important driver to build systems in place to help take some of the burdens of the individual and so from a systematic and transformational perspective, we are creating systems to drive and improve health outcomes with individuals and, of course, across communities.

We have a suite of tools and services that do this and many of these steps are important in this space that has already been indicated there is, of course, a big conversation in each of these steps. One, how do we identify social needs that exist within the populations that we are serving and how do we cultivate conversations that are at the provider and client relationship level. And then how do we get individuals enrolled in social care programs and ensure that not just the referrals are sent but ensure the services are delivered. And as that work occurs, we have the Unite us one of our core products is our platform, which is the shared technology across which the network is doing this work.

If we are doing this work on a platform, really important conversations about data and how can we use that data to monitor outcomes, to monitor referral activities, to monitor the populations that we are serving to be able to look at that data through the lens of equity broken down by race, ethnicity, age, gender, and so on. And using that data to spur conversations, self-reflective conversations within each of the organizations and certainly within Unite us. And those conversations across the community and across the network of organizations that are opting in to work together in this new way so that we can use that data to fuel smarter, more efficient, more effective, whole-person care delivery across time.

And then the final arrow here, the investment arm is more than just connecting individuals to care. This is also part of broader systems transformation. Many states are weaving this into the 11-15 waiver. How do we incentivize and create mechanisms to pay community-based organizations for the delivery of those services that Unite us has built into our product suite a tool that enables that to happen. And one of the things that have been highlighted here is the point of equity is even just through the lens of clinical care as well as for social care just seeing and treating social care under the same lens and the

same way we treat clinical settings is a macro-system of equity that is important to mention. Next slide, please.

And this is just a presentation of some of the Unite us **[inaudible] [05:06:46]** services, but also how we think about equity when we are engaging communities across the country and as we are working with individual organizations from either local government, community-based organizations, and certainly from healthcare systems side, they are all on this journey together toward system transformation. Again, driven by large policies such as the Affordable Care Act and others that are at the state level.

And importantly, we should note that organizations are in different steps along the way in their care transformation journey and our model or our mission is to meet organizations where they are and to be a technology partner, both for that particular organization, and then with the communities that we are working with to help cultivate conversations and again, to use data as we are leveraging shared technologies across accountable networks to coordinate the whole person of care. How can we use data to claim insight into how that work is going and how we can improve together as a community?

Moving beyond just paying CBOs for that work, all of these are important, very deliberate steps toward that larger goal of consistent transformation. And I should say, my background is in policy. I spent several years in D.C. in the executive branch and at that time we talked about the triple aim and then moved onto the quadruple aim, and I have seen reference to quintuple aim. And it is really important when we think about systems transformation and where we are going as a country, what that means as equity. That is the north star and that is where we are. We are working towards it, and it will take all of us at the table to get there. Next slide.

Just a quick dive. This is our core platform and as I mentioned like we do cultivate networks of organizations that **[inaudible] [05:08:06]** are working in a way and what they are doing is using the shared technology. This is shared technology that exists across that care continuum from clinical settings, community-based settings, and local public program settings. There is an important conversation about interoperability here and Carlos will be speaking to that in a second. Just to highlight a few key steps, we support the screening agnostic, but we support from a workflow perspective social needs screening tools not just referrals and then gets in over our platform, but the outcomes of those referrals are shared back as well.

As that patient goes through her social care journey, that longitudinal care journey is kept. And again, through the lens of transformation here, and through the lens of providing whole person and trauma-informed care, visibility into a number of those services are certainly important and we are not asking a patient, unless they so choose, to retell their story every time they interact with an organization within their community. So, information sharing is critically important to ensure whole-person care delivery and to ensure the integrations between clinical and social care settings.

With that said and certainly if you can go to the next slide, it is pretty self-evident. We recognize that privacy and security are super important and ensure that happens in the right way. So just three high-level bullets here to land on this point and one is we have consent-based into our models. And no information is shared on behalf of the client across an accountable network of organizations without the explicit consent of the client. And as I was just referencing there, while visibility to the care journey is really important to ensure that care delivery is trauma-informed, certain information should not be visible and that is particularly true for sensitive information such as substance use disorder, treatment information, and personal violence

information, that which will be covered by HIPAA and/or 42 CFR part 2 -- and all of those protections in place to ensure that information is not visible to organizations across the network. Finally, security is a massive point here. Unite us platform, our core platform, is high trust **[inaudible] [05:11:18]** is NIST certified and happy to dive in, in future conversations to exactly how we go about doing these things, but these are the three highlight bullets we want to land on when we talk about privacy and security. With that overview of the Unite us, I will kick it over to my colleague, Carlos.

Carlos Uriarte

Thanks, Read. If you can flip to the next slide. At this point, I want to bring it back to the discussion about health equity and how we think about health equity at Unite us. Advancing health equity is not just about connecting people with social care but it is about investing in that system's transformation that Read was talking about. So, what does that mean? It is about empowering the community through a no wrong door approach. So that individuals can find help and get connected to the help that they need wherever they are most comfortable doing so. It is about breaking down those silos between health and social care which is empowered by the kind of information sharing that we have been talking about today. It is about investing in the community and expanding the capacity of organizations in the community so that they can meet the needs of the communities that they serve. And that is through some of the sorts of systems and processes that others have talked about and Read just talked about in terms of providing payments for social care services in the same we would in a healthcare setting.

Finally, it is about responsibly collecting and analyzing data and providing that data back to the community and policymakers so we can make informed decisions about what is going on in the community, what decisions are made and how are the steps that are being taken impacting the different communities. Next slide. And we recognize this. This is just sort of a graphic here that shows all of the different sectors that are involved in bringing this to life and what that means from a systems and technology perspective and highlights why having clear consistent standards is so important. That interoperability is going to be vital to information sharing. And so, on the next slide here. Sorry, can you jump to the next slide? Yeah, thanks.

You know, what can ONC do to advance health equity from our perspective? One, it is about advancing standards of conversations to break down those silos between health and social care. So that is supporting interoperable stands like HL7 and FHIR and the OCR and PRM which was referenced earlier, which will be great in terms of clarifying the rules of the road here, particularly around privacy. It is also about having mature standards on the data collection and data reporting front and that includes social needs screening, appropriate demographic information being collected, and again that outcome reporting and information and analysis that will drive smart public health decisions.

And finally, you know, ONC in its coordination has the opportunity to really look across the Federal Government at all of the different ways in which government agencies are investing in social care technology infrastructure and making sure there is coordination across things like housing, food, transportation, et cetera, and using their authority to make sure again that funding is being used strategically and the standards are being developed in a coordinated way. With that, I will say thanks to everyone for the time today appreciate the conversation and appreciate you taking the time to listen to us.

Aaron Miri

Excellent. Excellent presentation. Thank you all and great. By the way, you offer a great service. Just know that I appreciate the work you are doing in the community. All right, next up, you got Dr. Williams.

Trenor Williams

Thanks so much, Aaron. Thanks to ONC. Thanks to the committee and the chairs. And thanks to my colleagues and peers on the line. Janet, Bob, Jaffer, Carlos, and Read. I will do my best to clean up now at the end of this. I am not going to use any slides and I thought two things, one, having a conversation about what we are seeing in the market is not going to be advisement for what we do but instead what is important and where we see the world a little bit and hopefully that perspective is helpful.

I wanted to start with the concept of visibility. Really simply. And actually, when we do use slides and when I use them, we start with a picture of Fenway Park, and for those of you in Boston or if you are in Wrigley Field in Chicago, you can go to one of their stadiums and buy seats behind a pole or a stanchion and you get this limited view of the field and what is happening. You pay money and you sit there, and we use it as an example frankly of what is going on in healthcare. We operate with a limited view of what is happening in healthcare to the people that we care for and that we care about, and we do it every single day. We use the information we have that happens inside of the four walls of a clinic, a hospital an emergency room, and try to do the best we can to better understand what is going on with somebody's life that is part of that. And I would argue that having visibility into those factors, both the risk that people are exposed to and the risk they have in their needs, is the first step in creating an equitable healthcare environment.

So, a couple of thoughts are tied to that. Number one, some of the things we talked about today, I just want to make sure we highlight vulnerable does not mean Medicaid. It is important to think about that and not just Medicaid or uninsured. We see, unfortunately, real social risk and social needs in every population and every insurance type whether that is seniors that have social isolation and challenges with transportation and health literacy. Think about commercial populations who have high deductibles, low-wage workers that might have to live farther from their place of work because of cost. They do not qualify for state and federal programs. In many cases, they may have a higher risk than an individual who has Medicaid as their primary insurance and qualifies for other needs. I think it is important that we think of this holistically.

The second thing is that a patient does not mean a person. We think, and I am a family doc, my background I am the son of a social worker as part of that. And in my practice when I practiced full time as part of that, I see a person in a certain way as my patient. Health insurance companies see them as a number and an employer sees them as an employee. A pharmaceutical company might see them as a clinical trial participant and non-profits see them as somebody that might seek their services. They are just a person. And I think one of the interesting things and I realize ONC has limited authority as we get outside of the provider space and unfair to ask you to do too much but we have to think holistically about the needs that people have and all of the different resources that are available to better support and address those social needs that somebody has. It cannot all be put on the back of a provider or a provider organization if we expect to drive outcomes, we have to be able to leverage the work that, again, our partners and the insurance space and the life science space and non-profit and government space and what they do.

Then the third piece around visibility is that it is not just the person level and based on my own personal attributes, we think a lot about the difference between social determinants of health. The risk exposure is based on where I might live, social risk. So based on my attributes, what are my specific risk and social needs. When do I go into a space that migrated from me, not at risk to having needs? An example of that might be based on the lack of healthy, affordable food options around me, I live in a food desert. Because of my income and family situation, I may have a risk for food insecurity, especially in the fourth week of the month. And in that fourth week of the month, I may transition from being at risk to having real needs. And I

think it is important as we think about how we will solve and intervene and do it at scale and in a repeatable way, that we understand the differences between each of those concepts as part of that. That is the first piece of visibility.

The second and I will hurry up a little bit from now on. The second piece is as we think about the social determinants of health and social risk and needs, we found real value in understanding both community risk and individual risk and what that looks like. So, when you think about the risk exposure based on where somebody lives and go back to the idea around food insecurity because is an easy one to talk about. Knowing where fast-food restaurants are and full-service grocery stores and food banks are as part of that ratio and based on where somebody is, what is their risk for food insecurity? They do not have access to healthy food options. It increases their risk as part of that.

And just as important is my risk and based on my situation the language that I speak, my family situation, the number of people in my household, my housing situation, the income I have or may not have, both are important. We think it is an "and," not an "or." If we are going to address and make investments in the community at the population level and individual level it is important to gain visibility for both of those topics, community, and individual.

The third piece is we found it invaluable to think about social risk and social needs at a domain level. What I mean by that is being able to characterize and quantify food, housing, transportation, health literacy, financial strain, we talked a couple. Bob Murry did a nice job talking about the digital landscape and digital literacy and we think about social connectiveness. And the reason we think about rather than a roll-up of social risk, it is just like clinical risk. If I knew somebody had a high HCC score, I am not sure as a family doc I would know what to do except for figuring out which disease it is. We are contributing to that. Same thing with social risk. It is important to understand the specific domains because as we think about whether that is a referral to community-based partners or an own intervention that an organization runs or care management even, knowing whether it is food and knowing whether it is housing or both matters. And even within that understanding that if you are thinking about food, understanding if it is affordability, availability of healthy food, or food literacy that is driving it, will help organizations think about how to cater the right precise intervention for that person and the right population.

Second to the last piece is as we think about this we talked about the identification and Dr. Murry you talked a little bit more about it and that integration and analysis. I will walk you through what we have seen to be valuable. Four steps. The first of which is that characterization, identification, risk, and understanding that a person at a community level for whole populations. Second, as part of that is being able to integrate that with healthcare data so we can look at the relationship between social risk at each of the main levels and disease and utilization patterns. So, it can know my diabetics who have food insecurity and transportation and what impact that is having on their experience, on outcomes, on quality scores, on utilization patterns, and quantify where it is having an impact.

Third, importantly, is prioritize the actions that organizations take. Whether that is optimizing care management and care coordination for that individual it is referring them to a community-based partner. We just heard two great examples around it is launching, building, and running an intervention like organizations like Granetica in Toledo, Ohio, do around financial opportunity where market-based, food-based programs are part of that. Understanding how best for which population has the most addressable risk and then the fourth piece is measuring all of that. The return on investment and not just financial return,

although that is important. Clinical return, experiential, and things like again Granetica with the financial opportunity center and able to measure the change in income that an individual has after they go through that program.

The last piece, I promise, is just an example. As we think about how we pull organizations together and again, think about a person and not just the patient or a member or employee. So really good example, I live in Washington, D.C., where an organization called D.C. Greens is a non-profit working with AmeriHealth which is a Medicaid plan, five different heavily qualified healthcare centers on the provider side, and the D.C. government. Identified individuals with diabetes and hypertension and enrolled them in a reduced prescription program where they give $20.00 per person per month for those individuals who redeem it at the pharmacy there and they get a nutritional consult. They go through that program and get $20.00 a week, up to $80.00 a month and renew it with their primary care doc who drives that referral every three months. And seeing more than 30% reduction in low **[inaudible] [05:24:54]** visits, and avoidable in-patient admissions and it takes all of them. Government, payor, provider, retailer, and the patient in the middle of that.

So, it is ONC that thinks about the opportunities that you have and how can you increase the impact that we all want to have on communities across the country. There have been so many great recommendations. The last one I will leave you with is tied to money. At the end of the day, how we drive the incentive-based program and reimbursement and whether that is to community organizations, and somebody talked earlier again about capacity building and Jaffer talked about capacity building funding as part of that. But incentivizing in the right way, organizations to invest in the space so that we can have an outsized impact on the people that need it the most in a scalable and sustainable way I think is critical. Thank you for the time. Appreciate the opportunity.

Discussion (05:25:49)

Aaron Miri
Fantastic. Thank you very much. All right. So, we are at a point of discussion right now for the next few minutes before we go to a break. And do I have HITAC members who want to ask questions, raise hands, please? I know it has been a long day on Zoom, but certainly, there have to be questions that are percolating on top of my mind for folks.

Clem McDonald
So, I have a question.

Aaron Miri
Go for it, Clem.

Clem McDonald
Let me get my video on. I do not know whether it is fair. The different products all are very interesting in this last session. And I liked all of them. How do they, I mean, can they interact? Are they there for different purposes? Are they overlapping? I do not get into the deep part of it. Could we get a sense of how they all fit or how things like that would fit into the world, whether they fit together or not?

Trenor Williams

And I do not know, but I will take it just because I jumped off mute first. This is Trenor Williams from Socially Determined. One, I think all of us are in this together. Think about the mission of all five organizations and our peers across that like we are all trying to do this and some of us may compete for dollars and business opportunities, but we are all trying to do the right thing. I will say for us, we are fortunate. We get to work with a lot of great health systems who have implemented Epic as part of that have started to implement the Socially Determined module and have taken great leaps as part of that. We get to work with the Unite us team and some of the large payor work that we do. We work with Jaffer and findhelp and I think, for us, as an analytic leader as part of that being in the middle of that ecosystem and having to work with, I think that is vital we work together as part of this.

Clem McDonald
That is good to hear.

Aaron Miri
Great to hear. Other comments, questions, thoughts?

Janet Campbell
I think one of the things that have been illustrated all day is that a lot of times the patients' particular needs are varied and the community-based organizations that serve those needs are a lot of them and are very small. So, I think it is kind of difficult to imagine, at least today, a world in which a single product could do all of that because that is the way markets work. So, I would underlie kind of what we heard all day and from others on this panel that the more we can develop interoperable standards for closed-loop referrals among all of the different programs, as well as with the healthcare side of things to the social care side of things and back, I think that's going to be key to strengthening the overall fabric of social care and support in the country.

Aaron Miri
Janet, I would add that with the establishment of the TEFCA and the Q-HIN work and everything else the data flow should help further augment, in a positive way, exactly what you said. Establishing more of those networks and more referral patterns and more of that data sharing. Again, that is a theory.

Carlos Uriarte
I would echo.

Robert Murry
Go ahead.

Carlos Uriarte
I was going to echo what you said about national standards and say that absolutely that is the thing that will help be the glue to bring this together. And allow everyone to play together in the sandbox in the way that Trenor explained.

Aaron Miri
Absolutely. HITAC, we have Ike.

Steven (Ike) Eichner

Thank you, sir. I think it is really important and I appreciate all of the presenters this afternoon, but I do think it is important that we make sure that the patients and their families remain at the center of care and play an active role in looking at the referral process. So that it is an action that is taking place in conjunction with patients and their families and not for or to patients and their families. Respecting patients' control and management of information and what gets shared with whom and under what circumstances.

One of the things I think that is easy to forget is particularly when individuals have complex cases or complex histories, there is a lot of information involved that may be necessary and useful in providing coordinated services and coordinated care. But taken as a whole, how many people are interested in if all the spectrum of their personal information is being shared with people that they do not know in a similar circumstance. I think it is important to remember that people are patients, but people are people too. And are interested in maintaining privacy and confidentiality and control, ensuring what they want to share, how they want to share it, and not having it shared on their behalf outside of their control.

Trenor Williams
I am wondering if that was an open question to our panelists and if so, I can respond. I realize I was presuming.

Aaron Miri
There are other hands.

Steven (Ike) Eichner
And building on the presentation, figuring out how do we become a recommendation to ONC perspective come up with a set of parameters or set of recommendations that facilitates sharing of information across the provider continuum but also puts patients and their families in an important central role in managing that process.

Aaron Miri
Right. I think that is what we are all marching towards is getting that uniform set of industry-accepted principles and regulations there. That is a good point. Before I go to the next hand raised. I just have a comment here. Dr. Murry, I think you may have been trying to say something, and apologies we missed you because a lot of people were talking. Do you still have a comment or are you good?

Robert Murry
I think we are good. It was back to the previous question, but the question was how the five presenters the example organizations work together, and I was going to make two points. The first is that there is a lot of collaboration now with the two main nationwide interoperability networks which play a big role. Commonwell and Carequality. And when I was describing my take on interoperability from the provider standpoint as being able to know there is data out there and incorporate that data in, a lot of that can be automated through those networks. It is used to construct the clinical longitudinal patient record but included within that is a lot of the social determinants and other health equity data that can then, through HIEs or directly from the EHR or other exchange mechanisms like direct messaging or FHIR API, can be used to send the data to and receive it from the social service agencies. So, some of that is the future state, but a lot of that is happening now. It is just a matter of providing everyone access to the interoperability plumbing and the networks so that the exchange can begin to happen.

Aaron Miri

And I would say Dr. Murry with my chief digital hat on that, not every vendor plays in the same sandbox the same easy way so not every provider organization can contribute as much data as they would like to some of those readily available nationwide networks, I would encourage everybody to send them through those national networks and get this going because your respective vendor may tell you don't need to worry about them. Keep your data in our data specifically. It does not mean it is the right thing to do. Dr. Murry, you are exactly right. In practice, it becomes difficult.

Steven (Ike) Eichner

And this is Steve Eichner, again, looking at connected at the national networks with the appropriate security and controls so that the patients and their families remain as an important central component and providing access and gatekeepers for that information.

Aaron Miri

That is right. That is exactly right.

Robert Murry

And Aaron, as you know and the committee knows there are proposed standards for that, right? Security tags their latest name not required but the idea is at a very granular level within these health IT systems, patients and providers can designate which portions of the record can be shared and have that consent needs to travel with the data itself across these networks. Those standards still need work and consensus and clinician involvement and social service involvement and then, of course, they need adoption which is not going to happen spontaneously.

Aaron Miri

Our committee for USCDI and also the **[inaudible] [05:35:12]** committee. We have some phenomenal clinician leaders at the table. To your point, I feel pretty good we are on the right track but as we said earlier in this session today, we have been saying it before, hopefully, we can accelerate the center adoption. I believe Dr. Lane said that today. And I agree with that. As we get better and more mature in it. But we at least have a path, and we are going down that path. We just need to put some gas in the accelerator and keep going. I appreciate your words, Dr. Murry. It is very well-spoken. All right. Back to the queue here. John Kansky. Go for it.

John Kansky

Hey, thanks, Aaron. So, I think it is in juxtaposition because I, also, wanted to weigh in on Clem's original question of how can this, how does this fit together? And the mental model which I think is somewhat complementary to what Dr. Murry said and in maybe some ways an alternative. If you think about a robust statewide health information exchange having participation from conventional sources like hospitals and payors and thinking about the data that is generated through conventional healthcare and then you just widen that definition of healthcare and that view of healthcare can include community-based organizations and social determinants data, the health information exchange can provide the same purpose in connecting and achieving some of those needs for close loop referral and we have to widen the circle to include community-based organizations and the types of intervention systems and data they use into the health information exchange circle however we achieve that.

Aaron Miri

Good points. Good points, John.

Robert Murry

I agree. When we talk about HIEs as utilities, they are connecting data providers with data consumers. But some of this is happening spontaneously. There are some amazing HIEs out there, but we also know that many other HIEs are losing their business cases, losing their funding, and closing. So once again, without coordination at a higher level, this opportunity that they could play that you just described again is not going to spontaneously occur.

Aaron Miri

Yeah. I would say we would be much better off as a country if there were more HIEs around like Indiana is run because that is a well-built model with phenomenal organizations like **[inaudible] [05:37:39]** sharing data robustly across a region. It is amazing, same with Massachusetts, and same with Arizona. I mean, there are phenomenal examples of how to do it right and phenomenal examples of the way to do it wrong. Spot on point. Spot on. All right. Next up in this list, Sheryl Turney

Sheryl Turney

Can you hear me?

Aaron Miri

Yes ma'am. Well, you are echoing.

Clem McDonald

We hear you many times.

Aaron Miri

Interoperability issues.

Sheryl Turney

I was having trouble with my audio before, so I had to call in. It looks like it is working now. I wanted to thank everybody for speaking today because I think this was a very important topic. I also wanted to re-enforce the issues that everybody has brought up in terms of making all of this work together. And at the end of the day, it requires a lot of coordination, testing, funding and, with healthcare being a business model, it is like I think we need to work together to make sure the business models support all of these services so the right people can get access to the care that they need.

We heard from a variety of speakers and topics today and it makes me so emotional because, with so many of the challenges that we are described, I can identify with those happening to people in my family. I have an aunt that cannot get to a doctor's appointment because the transportation does not show up. And takes a phenomenal amount of work to schedule the nursing home, the doctor, the transportation, the person who is going to be at the appointment, and all of these services are performed by people. And people make mistakes. And they do not have the right appointment services, et cetera. So, you know, to me I want to look at everything we are doing from the point of view of a patient who is getting care.

I have another family member who was misdiagnosed now, had cancer, but was diagnosed with another cancer, and still, four years later that is still on her record. She cannot get it changed because of the systems that we were talking about with problems earlier. There are problems we need to solve but unfortunately, a

lot of those problems are going to take time because the funding and the business model is not there to support these services in an accelerated way. And also, I think we need to be careful about some of the AI models that are being used. There is a lot of attribution going on today and the mechanisms that vendors are using for testing those attribution models are not wide enough distribution of population that they are using for validation.

We are an entire country of many blended families today and attributing race, ethnicity, and language to family members in that model is something that needs extra care. And also, the issues that were brought up earlier about access to devices. That is another situation where there are individuals especially older ones who cannot use a device. They do not have the capability because they lost their memory or they have lost their ability to reason or whatever the case may be, speaking from my own family personally. Those are things, how do you bridge that challenge. You work with all of the supporting people and still, it does not happen the way it should happen. So, I would just be interested to hear how people think like what is the thing if we were going to have a lightning bolt. I am a problem solver. What is the bolt that we need to motivate this to move forward? This is great to have this hearing but what is the call to action?

Aaron Miri
Great point, Sheryl. No, that is exactly right. I do not know if anyone on the panel wants to answer that from your perspective on the work you are all doing.

Janet Campbell
As I mentioned, I think one of the most important things we can do now is focus on an accurate collection of data. Not just race, ethnicity, and language but other data as well. To do that we need to not just look at technology and standards, we need to look at operational procedures and policies, and then we can take those and apply them to the quality reporting that already happens today. There is a ton of quality reporting that is happening and to a certain extent, that is stratified the way we should stratify it, but we need to make that public and transparent and use it for decision making. And the reason I say that that is what I would wave my magic wand at is that I think it is achievable and I think that there are other things in place that are happening that are going to go much, much farther but that is something that we can all do right now today that I think would give us a much better picture of what is going on in this country than we have currently.

Carlos Uriarte
I have to agree with all of that and I would say also that going back to the comments from the presenters earlier there is also this community to ensure that we are making the right investments and creating the right incentives for those investments to be made both in the infrastructure is that needed to make the information sharing happen and as well as investments back into the communities and the organizations that are providing these services. I think to the point about what is the charge here, I feel that would also be a great outcome here on something that is certainly achievable.

Read Holman
If I could add to my colleague Carlos, the question of course Sheryl and thank you for sharing some of your stories. It comes down actually to the question of power. Who has the power to shape those policies and to shape those incentives? And I think there is a really important role that we all play in ensuring and not just including the community voice on just, not including your stories at the table but elevating. There is a long history of imbalances in power I think that got us here and I think the path forward is about correcting

that. And that includes governments within communities, of course, and governance across standards-making bodies, such as HITAC.

Aaron Miri

Any other comments?

Jaffer Traish

One quick comment. This is Jaffer. I with ant to echo Janet's comments as well on the data collection. But what we have learned is very good data collection and we bring that needs-based data with the hands of those with the funding capacity whether it be government or whether it be philanthropy or whether it be actual healthcare organizations themselves who do significant amounts of charity-based work or donation-based work. They can power how those dollars to fund capacity in a community to drive better coordination on behalf of the families who need it. And Michael Susan Bell Foundation putting forward millions of dollars to remove the barrier of funding from a cross-system care coordination model is incentivizing the standards, work, the data collection work, and care coordination work. The LEAP grant of course, that all coming together is doing some very special stuff in that community. So, I think it is a combination of what Janet shared plus who we bring that data to so that we incentivize the right dollars.

Aaron Miri

I would agree. I have my CIO hat on **[inaudible] [05:45:40]** Folks like Epic, Janet, Nextgen, others, we look to you and especially in the provider community for that guidance. Even the relevant I will use Epic terms, the relevant Sherlocks that reference EHI putting in their comments around social determinants and how to release that data just to teach the community. It continues to re-enforce this notion of all data is relevant. All data has a place. How do we get that back out there to address some of the earlier issues? Specifically, Janet, I would point you to Sherlock 103720 and add something in there about social determinants that will be helpful. Sorry, I am not a Nextgen customer, otherwise, I would tell you about a respective one there, but to a degree of it, all of those opportunities will keep this going. All right. Real quick, Clem, please, we have got about a minute and a half. Go for it.

Clem McDonald

Am I on mute?

Aaron Miri

Nope, we can hear you.

Clem McDonald

A couple of points. One is that everything does not need money and more effort. A lot of it is policy tangles or policy nats. For some of these kinds of data, we could get it from Medicaid if they allowed it or the social services if they allowed it. This stuff is collected in a lot of different places, but it is hardly ever connected and partly because of policy. The second thing I wanted to bring up is we heard in this last session how important standards are. Doing it the same way. And then we heard earlier that, well, we are not going to do it the same way because we have to allow people to be inventive. Those are contradictory goals. If we will have standards people have to give up one way of doing it or give up a couple of ways. A few ways. That is all. Thank you.

Aaron Miri

Sorry, I was on mute. All right, we are exactly at time, and I see no more hands raised so I am going to presume that is it. I want to thank all of the panelists and if, you know, I appreciate everybody today that has been here and has given voiceover. But if you are ready for this and Denise let me know if you have comments or questions and I think we will go to public comment.

Public Comment (05:47:47)

Mike Berry

All right. We will look to open up the meeting for public comment now. So, if you are on Zoom and would like to make a comment, please use the hand raise function which is located on the Zoom toolbar at the bottom of your screen. If you happen to be on the phone only, press *9 to raise your hand, and when called upon, press *6 to mute and unmute your line. We will pause for a moment to see if we have public comment. I want to remind everyone that the next HITAC meeting is held on April 13 and all of the materials today, the slide presentations, testimony, bios can be found on the HITAC website on healthIT.gov. I am not seeing any public comment, so I will turn it back to you and Denise to close us out.

Closing Remarks (05:48:34)

Aaron Miri

Yeah. Denise, you want to start? And I will close out.

Denise Webb

Sure. Well, I want to thank everybody for participating today and especially thank all of our presenters, and for their thoughtful, informative testimony. Certainly, filled my head up with a lot of things to think about and ponder. And thank you ONC for making this happen. Appreciate it a lot.

Aaron Miri

Yeah. And I would say I want to echo a lot of it. Today has been a personal day for a lot of folks sharing personal stories which made it impactful. You heard phenomenal presentations by our panelists making an impassioned plea for us to please help them move the ball forward and all of this good work that is going on and galvanizing the industry. I think it speaks exactly to what Micky and others were saying earlier today about the importance of this topic and how resonating it is. Down to the fact-finding. Personally, I am the son of two first-generation immigrants, my mother from El Salvador and my father from Iran. Both came here and worked their way to the American dream to give a life to my brother and me and they did but not without language barriers and other issues they had to overcome. Everybody has those challenges so the more we can democratize and make equitable healthcare delivery, the better for all and that is exactly what we stand for. I applaud all our presenters and applaud this committee. Thank you for your engagement and your questions and answers today. It has been a phenomenal organization and a phenomenal time with you all. So, thank you. With that, Mike, Denise. I think we are ready to say sayonara.

Mike Berry

Okay. Thank you. Okay, everybody. Thank you for joining and thank you again to our presenters and our meeting is adjourned. We will see you next month.

Aaron Miri

Thank you.

Adjourn (05:50:20)