



Transcript

HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC) MEETING

May 16, 2024, 10:00 AM – 1:00 PM ET

VIRTUAL





MEMBERS IN ATTENDANCE

Medell Briggs-Malonson, UCLA Health, Co-Chair
Sarah DeSilvey, Gravity Project, Co-Chair
Shila Blend, North Dakota Health Information Network
Hans Buitendijk, Oracle Health
Michael F. Chiang, National Institutes of Health
Derek De Young, Epic
Steven (Ike) Eichner, Texas Department of State Health Services
Lee Fleisher, University of Pennsylvania Perelman School of Medicine
Hannah Galvin, Cambridge Health Alliance
Rajesh Godavarthi, MCG Health, part of the Hearst Health network
Steven Hester, Norton Healthcare
Bryant Thomas Karras, Washington State Department of Health
Hung S. Luu, Children's Health
Trudi Matthews, UK HealthCare
Anna McCollister, Individual
Deven McGraw, Citizen
Katrina Miller Parrish, Patient.com
Aaron Neinstein, Notable
Eliel Oliveira, Harvard Medical School & Harvard Pilgrim Health Care Institute
Kikelomo Oshunkentan, Pegasystems
Randa Perkins, H. Lee Moffitt Cancer Center & Research Institute
Rochelle Prosser, Orchid Healthcare Solutions
Dan Riskin, Verantos
Mark Sendak, Duke Institute for Health Innovation
Fillipe Southerland, Yardi Systems, Inc.
Zeynep Sumer-King, NewYork-Presbyterian
Naresh Sundar Rajan, CyncHealth

FEDERAL REPRESENTATIVES

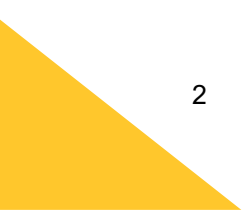
Keith E. Campbell, Food and Drug Administration
Jim Jirjis, Centers for Disease Control and Prevention
Meg Marshall, Department of Veterans Affairs
Alex Mugge, Centers for Medicare & Medicaid Services
Ram Sriram, National Institute of Standards and Technology

ONC STAFF

Steve Posnack, Deputy National Coordinator for Health Information Technology
Elise Sweeney Anthony, Executive Director, Office of Policy
Avinash Shanbhag, Executive Director, Office of Technology
Seth Pazinski, Designated Federal Officer

PRESENTERS

Peter Karras, ONC
Dustin Charles, ONC
Leonie Misquitta, ONC
Thomas Mason, ONC





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

Seth Pazinski

Hello and welcome, everyone, to our May HITAC Meeting. I am Seth Pazinski with ONC, and I will be serving as your Designated Federal Officer today. This meeting is open to the public, and I wanted to remind the public who are joining that you are welcome to participate with comments throughout the meeting in the Zoom chat feature. And, we also will have the opportunity for a verbal public comment at around 12:50 p.m. is scheduled on our calendar for today. Let us get started with our meeting. First, I wanted to welcome ONC's executive leadership team during the meeting with us today, which includes Steve Posnack, our Deputy National Coordinator; Elise Sweeney Anthony, the Executive Director for the Office of Policy; and Avinash Shanbhag, our Executive Director of the Office of Technology. I will next begin our roll call of the HITAC Members. When I call your name, if you could indicate that you are present. And I will start with our co-chairs. Medell Briggs-Malonson.

Medell Briggs-Malonson

Good morning, everyone.

Seth Pazinski

Good morning. Sarah DeSilvey.

Sarah DeSilvey

Good morning, all.

Seth Pazinski

Shila Blend.

Shila Blend

Good morning.

Seth Pazinski

Hans Buitendijk.

Hans Buitendijk

Good morning.

Seth Pazinski

Michael Chang.

Michael Chiang

Good morning.

Seth Pazinski

I did get a message that Derek De Young will be joining us a little bit later today. Steven Eichner. Lee Fleisher.





Steven Eichner

Good morning.

Seth Pazinski

Lee Fleisher. Hannah Galvin.

Hannah Galvin

Good morning.

Seth Pazinski

Rajesh Godavarthi.

Rajesh Godavarthi

Good morning.

Seth Pazinski

Steven Hester.

Steven Hester

Good morning.

Seth Pazinski

Bryant Thomas Karras.

Bryant Thomas Karras

Present and accounted for.

Seth Pazinski

Hung Luu.

Hung Luu

Good morning.

Seth Pazinski

Trudi Matthews.

Trudi Matthews

Hello, everyone. Good morning.

Seth Pazinski

Anna McCollister.

Anna McCollister

Good morning.





Seth Pazinski

Deven McGraw.

Deven McGraw

Good morning.

Seth Pazinski

Katrina Miller Parrish.

Katrina Miller Parrish

Good morning.

Seth Pazinski

Aaron Neinstein.

Aaron Neinstein

Here.

Seth Pazinski

Eliel Oliveira.

Eliel Oliveira

Good morning.

Seth Pazinski

Kikelomo Oshunkentan.

Kikelomo Oshunkentan

Good morning.

Seth Pazinski

Rhonda Perkins.

Randa Perkins

Good morning.

Seth Pazinski

Rochelle Prosser.

Rochelle Prosser

Good morning.

Seth Pazinski

Dan Riskin.



**Dan Riskin**

Good morning.

Seth Pazinski

Mark Sendak. Fil Southerland. I thought I saw Fil. Fil, I see you on there. You are not coming through on audio. Zeynep Sumer-King.

Zeynep Sumer-King

Good morning.

Seth Pazinski

Naresh Sundar Rajan.

Naresh Sunder Rajan

Good morning.

Seth Pazinski

And now, I will do roll call for federal representatives of the HITAC. Keith Campbell.

Keith Campbell

Good morning.

Seth Pazinski

Jim Jirjis.

Jim Jirjis

Good morning.

Seth Pazinski

Meg Marshall.

Meg Marshall

Good morning.

Seth Pazinski

Alex Mugge.

Alex Mugge

Good morning.

Seth Pazinski

And Ram Sriram.

Ram Sriram

Good morning.



**Seth Pazinski**

Thank you. Is there anyone I missed or who joined us after the roll call? All right.

Lee Fleisher

Lee Fleisher. Sorry. I am just joining.

Seth Pazinski

Thank you. Please join in welcoming Elise Sweeney Anthony for her opening remarks.

Welcome Remarks (00:04:21)**Elise Sweeney Anthony**

Good morning, everyone. It is a pleasure to be here today. I am always so appreciative of our HITAC meetings, not only because of the feedback that we are able to receive in our work at ONC but also, because I have a strong appreciation for the volunteerism and the amount of time that the members spend focusing on issues of health IT that help ONC as we consider our next steps. Thank you so much for everyone joining. Some of you are joining super early and so, we appreciate that as well. Today, I am going to give a couple of updates from ONC since our last meeting. And, of course, if you have any questions, let me know. We recently celebrated our 20-year anniversary, April 27, 2004. That is when there was an executive order established focusing on ONC. And we were established through that executive order. And to go from where we were at that point, to where we are now, we are really excited for that milestone.

We also know that there are many steps for us to continue to grow and many areas of health IT for us to continue to work on. But we are really excited for this really hallmark moment of our progression and also huge appreciation to our staff who work tirelessly day after day on a range of health IT issues from policy world to the technology world, to the operations team that support all that we do at ONC. I just want to give a huge appreciation to the staff and our leadership from all of the leadership across ONC, especially Micky Tripathi who is not here today. But it is a great opportunity for me to talk about him and just show appreciation for all the work that he has done and all the leadership that he provides at ONC, as well as our Deputy National Coordinator, Steve Posnack, who is on the line, as well as Lisa Lewis, who is our Deputy National Coordinator for Operations. And amongst the three of them, the support that they provide to the team is just amazing and we are truly appreciative.

Happy anniversary, ONC and more to come in terms of the great work. Check out the blog that we also put out regarding this as well. A couple of things that we wanted to give you an update on in terms of the work streams that we have engaged in. One is the Trusted Exchange Framework and Common Agreement (TEFCA). The work there continues. ONC and the Recognized Coordinating Entity (RCE), which is the Sequoia Project, released the Common Agreement Version 2. We are really excited about that release because that includes a number of things that folks will know, including brings Fast Healthcare Interoperability Resources (FHIR) into the world of TEFCA. When we think about application programming interfaces, when then think about FHIR, that is a lot of what we encompass our activities at ONC. We think about that for our landscape. And we are excited to see FHIR brought into the V2 landscape as well.

There are seven designated Qualified Health Information Networks (QHINs) under TEFCA. And now, they are able to adopt and sign and implement a new version of their Common Agreement Version 2. We are excited for that as well. We believe that these enhancements and updates mark a really huge step forward





for TEFCA and it meets the promise we are trying to achieve in terms of moving exchange at scale at a nationwide level. The other thing I wanted to update folks on is our DaVinci prior authorization test kit. And this was recently released. It is a new voluntary test kit. It provides developers and other health IT implementers with a tool to test health IT system support for prior authorization using the HL7 FHIR standards. Finally, a reminder that the public comment period for the 2024 standards version advancement process, which we call SVAP, is open until May 21, 2024. That is right around the corner as folks know. I want to encourage you to check that out and let us know if you have any thoughts by submitting through the comment process.

In closing, I just want to thank everyone for their support of ONC throughout the years and for all of the support to come as well. We really appreciate it here at ONC. And we are excited for what the next 20 years will look like. I will turn it over to Medell and Sarah for their opening remarks.

Seth Pazinski

This is Seth. I just want to jump in with an admin update from the DFO. Thanks, Elise. I wanted to inform folks that the HITAC Annual Report Workgroup is going to begin the development of the fiscal year 2024 report with a kickoff meeting on June 3. The roster for that workgroup is almost full. And we have had a wonderful response of volunteers who are interested in serving on that workgroup. And I want to thank everyone who has raised their hands to participate. But if you have not had a chance to volunteer and are interested in that workgroup, if you could please notify me by close of business tomorrow on March 17. I much appreciate it. And we will plan to finalize the annual report workgroup roster, as well as select our new workgroup co-chair to serve alongside Medell for this year's report cycle. With that, I will turn it over to our co-chairs Medell and Sarah for their opening remarks.

Opening Remarks and Review of the Agenda (00:09:43)

Medell Briggs-Malonson

Thank you so much, Elise and Seth. And congratulations to ONC for 20 years of remarkable service and impact. It is our privilege and honor to serve alongside you as HITAC. And we also look forward to all of the many years to come and all of the impact ONC we will continue to have. Good morning, everyone, and welcome to all of the HITAC members. It is always such an extreme pleasure to meet with all of you and go through some of the topics we will go through today. We have several exciting items on the agenda. And please make sure that you share your perspectives and insights because we hope this will evolve into even more of those impactful conversations and services and actions in the future. Sarah, I will turn it over to you.

Sarah DeSilvey

Thank you so much. I will just reiterate Medell's appreciation and congratulations to ONC. It is an honor to work alongside ONC on many projects and, especially an honor to sit here with Medell and help co-chair HITAC. I also want to reiterate Elise's statement and gratefulness for the volunteerism of all of the HITAC members that show up here once a month and all of the many work group meetings to make everything happen. I want to briefly just go through the agenda before we kick off the rest of the work. We have already covered call to order and roll call, opening remarks and then, our next topic is to review the Federal Health IT Strategic Plan. We will then have a conversation on a topic that is very near and dear to the work that we do at Gravity and my own work, which is United States Core Data for Interoperability (USCDI)+ and maternal health. We will take a break at noon. At 12:10, we will reconvene through another ever so critical





topic, which is advancing Health Equity by Design in Health Information Technology. We will then have public comment at 12:50 p.m. and adjourn at 1:00 p.m.

A very lively and prescient and important conversation furthering ONC's conversations regarding health equity across the ecosystem. And now, I am transitioning to Medell.

Medell Briggs-Malonson

Absolutely. Thank you so much, Sarah. I would like to introduce Peter Karras and Dustin Charles who are going to provide an overview of the draft 2024 to 2030 Federal Health IT Strategic Plan.

Draft 2024 – 2030 Federal Health IT Strategic Plan (00:12:08)

Peter Karras

Thank you so much, Medell and Sarah. My name is Peter Karras and I am the Deputy Division Director within our Strategic Planning and Coordination Division at ONC. I am joined by my colleague, Dustin Charles, who was also in our Strategic Planning and Coordination Division. We are really excited to join HITAC and provide an update of our draft 2024 to 2030 Health IT Strategic Plan that is currently out for public comment. We can go on to the next slide. Thank you. Here is just the table of contents view and we will unpack this further as we move along the presentation. But before we dive in, I really did want to mention a couple key imperatives that ONC had in mind at the onset of the plan's development. And the first was to use plain language. This is a Federal plan designed to communicate to the public where we want to go, where we want to be, and why we want to get there.

The plan describes a destination that we strive to get to and that really is ultimately to improve health for all Americans using the conduit or the vehicle of health information technology. For that reason, we wanted a plan that is not only understood by providers or researchers or developers or HITAC members, but most importantly, the everyday person who does not play in this space other than the fact that they are just the recipient of healthcare services in this country. The other imperative when we released the draft plan was to not be too text intensive. We wanted to put it in a format that was digestible, easy to see, which would hopefully then mean if it is easy to see that it is easier to read. Then, making it more easier to understand and easier to work towards. It is a 27 slide strategic plan if you take out appendices and intro content so I know I am cheating a little bit. We think that is short for a government document with all things considered. We can go on to the next slide.

This slide is information on how to submit public comments and by when. And although ONC is facilitating the public comment process, I would be remiss if I did not mention that this is a federal plan that represents more than 25 federal organizations within various departments and components who contributed to its development. We still have some time before the comment period closes, which is on May 28. We ask HITAC members to continue to socialize the plan within your respective networks and encourage the target audiences who work with you every day to participate in the public comment process. We can go on to the next slide. This is a slide with federal health IT mission and vision. And the mission statement describes our purpose for existence, which to a certain extent really should be the same yesterday, today, and tomorrow. And that is to improve the health and well-being of individuals and communities using technology and health information that is accessible when and where it matters most.





Then, the vision statement is our tagline describing where we want to be or where we want to go and what we want to strive for. And that is an overall health system with engaged individuals, lower cost, high quality care, and improved individual and population health. Here are the four goals in the plan. And we are going to drill down and unpack these later into the presentation. But the first three goals describe the benefits that we want the population served by federal agencies to experience as a result of health IT and improved access exchange and use of electronic health information. And those are to promote health and wellness, enhance the delivery and expense of care, accelerate research and innovation. And the fourth goal focuses on cross cutting policy and technical foundation and infrastructure needed to support the advancement of the other three goals. And that is to connect the health system with health data.

This slide describes who we want to realize the benefits of these goals. And that is promoting health and wellness for individuals, populations, and communities and really extending that use case to leverage health IT to empower individuals, even when not in a formal care setting. Where people play, live, learn, and work, really to promote healthy behaviors. And then, enhancing the delivery and experience of care. For patients and caregivers who experience care but also, enhancing the experience for providers and others in the healthcare continuum who support care delivery. I think the point here is acknowledging that care delivery is a partnership between those receiving care and those who are delivering care. And that partnership is really important in acknowledging experience of care and delivery across all of those parties involved throughout the lifecycle.

The next is accelerate research and innovation by harnessing the power of data in equitable ways through collaborative efforts of researchers, developers, and other IT users. And lastly, connecting the health system with health data for all users of health IT so that the development of use of health IT capabilities continues to advance, that we continue to set clear and shared expectations for data sharing that supports everyone in the healthcare continuum. Although the development and the maintenance of this plan is a statutory requirement under the Health Information Technology for Economic and Clinical Health Act (HITECH) Act, we have seen it was, generally, a good time to update the plan just given several considerations to ensure the relevance of our health IT strategy and the current landscape and that we are evolving to meet the needs of the country and the American people, that we are constantly evolving in a way that just answers the needs of the people that we serve every day in this space.

And so, that involved having a focus on modernizing our public health infrastructure and also, recognizing the disparities in healthcare, access and outcomes, and because of that, seeking to remote equitable access to electronic health information, fair representation, and research endeavors so that research reflects the full diversity of the United States when it comes to the data that is being analyzed. And it ensures equity is built into health IT and those information systems. And then lastly, the draft plan acknowledges the evolution of artificial intelligence and its increased use in healthcare. I just really wanted to emphasize the need for transparency of those models and the effective use and how those patterns are recognized and ultimately put into care delivery.

The scope of the strategic plan, as I mentioned, is to broadly communicate strategic direction. And if we have to boil it down even further, our intent is to describe in a simple way what we want from an outcomes-based perspective, why we want it, who benefits, and for our purposes, the health IT strategies we want to pursue to get us to those outcomes. The plan is a communication and alignment tool describing strategic direction like a north star in terms of our efforts and priorities and monitoring progress against. The how, so





the specific programs, and projects to get us to those goals, those are reserved for strategic implementation that will communicate and continue to communicate progress on the out years using various mechanisms. I am not going to read off everything here. The main point is that our health IT strategy is a progression. I would like to say it tells the story. In the early days, it was educating the healthcare community on what health IT is and its value and then, moving to work towards digitization of health information as part of what was called to the meaningful use program.

And then, now it is in the information system, health information is digitized. Here are the benefits. This is what you can do with an electronic health record (EHR). In then now, the ongoing continuing effort to focus on exchange of that health information through various policy and technical activities to try and continue to connect the health data that is in these systems that might be disparate and have them be able to communicate and be shared in a meaningful way and in a usable way. This lists out our principles. And the way we can look at this is it is really a litmus test for decision making. The various work in realizing our strategy should align to one or more of our principles or values. If there is no connection then, we should revisit why or how we do the things we do in the first place. And those are person centered inclusive design. Putting individuals first and embracing person centered care that values the whole person and meets their needs. Safety and quality, focusing on safe and quality high-value care that really increases the margin between what people pay for and what people get.

Privacy and security, continuing to build trust and protect against misuse of the Electronic Health Information (EHI). Data led decision making, effectively translate knowledge into clinical practice to improve care and outcomes across individuals and populations. And then, increase health equity and advance the use of representative data sets to meet all individuals where they are. And then, encouraging innovation and competition through access exchange and use of electronic health information that promotes new business models and results in improved care, quality, value, and innovation. And we can move on to the next slide. This gets into our strategic plan framework. And I am going to turn it over to Dustin. He is going to unpack these goals and objectives in the next slide. Dustin, turning it over to you.

Dustin Charles

Thanks, Peter. Thank you for covering that. My name is Dustin, a senior management analyst at ONC. I will be covering, basically, the meat of the strategic plan, going through the goals and objectives strategies. I will not be reading each and every one of these directly but try to give an overall summary. But first, let me go over the goals again. Goal 1 is promote health and wellness. This goal is really focused at the individual population and community levels. And you will see that through the objectives. Goal 2 is enhanced delivery and experience of care. As Peter said, this is really looking at how patients and healthcare providers interact with one another to participate in our healthcare system. Goal 3 is accelerate research and innovation. This is really focused on a lot of the work that is done with health data to improve how healthcare is delivered, healthcare quality, and other ways of improving healthcare and innovation within healthcare and health IT.

And then finally, Goal 4 is the infrastructure goal that builds that infra structure for everything for Goals 1, 2, and 3. It connects the health system with health data, which is needed for those other goals to succeed. The first goal objective is individuals are empowered to manage their health. If we can just go to the next slide, we will go specifically through each objective and their strategies. The format we used here was a strategy and then, what the hopeful outcome or expected outcome will be. As you see, it is the federal





government plans to and then a so that statement. It sort of tells why the federal government wants to do this. As I was saying, the first objective is individuals are empowered to manage their health. These include strategies for improving and expanding secure and private access to electronic health information, protecting individuals' health information as well, and keeping individuals better informed on how their health information is used and how to protect it.

Here is individuals and populations experience modern and equitable healthcare. Strategies here are really built around providing individuals more tools to increase their understanding and use of health information. Also, to ensure that health information is useful to promoting individual and population health. Here is focused on communities. Communities are healthier and safer. The overall strategies here focus on improving how health data is shared and use at the community level. This includes electronic health information, as well as public health information. Going on to Goal 2, we will go through each objective as well. We can go to the next slide. Providers deliver safe and equitable, high quality and improved care. Under this objective, the strategies are about supporting health IT to produce higher quality care and improving data sharing accuracy and usefulness to providers.

Here is patients experience, expanded access to quality care, and reduced or eliminated health disparities. Again, the strategies here are really expanding access to health IT. This includes telehealth, as well as reaching parts of the healthcare system that have not seen as much advancement in health IT as we would like. Also in here, the strategies focus on greater integrations of healthcare and human services via health IT. This objective is healthcare improved through greater competition and transparency. The strategies support a safe, secure, and transparent healthcare marketplace, as well as looking at emerging clinical and administrative data, which is something we have recognized needs some more work. But there is a lot of value within doing that. Providers experience reduced regulatory and administrative burden. Under these strategies, we hope to simplify, streamline, and standardize documentation and data to allow for more automation.

We also want to increase the education of electronic health information sharing so that there is a safe and responsible use of things like artificial intelligence and the different types of algorithms and so forth and how they are used in healthcare. The last objective under Goal 2 is the healthcare workforce uses health IT with confidence. The strategies here support using health IT to improve healthcare workflows and promoting education and lessons learned sharing across healthcare settings. Now moving into Goal 3, which focuses on research innovation. Researchers and other health IT users have appropriate access to health data to drive individual and population health improvements. Under this objective, we really want to reduce the difficulties for researchers and others to have appropriate access to health data so that they can conduct their research. We also want to strengthen privacy and security around health data used in research. It is really finding that balance between appropriate access, as well as making sure the data is private and secure.

Individual and population level research and analysis are enhanced by health IT. Here, the objectives are increasing the capabilities of what health data can do to improve research, as well as increase transparency on how health data is used, particularly with AI systems. Here, it is researchers advanced health equity using health data. That includes underrepresented groups. The strategies here focus on improving representation in health data research and its outcomes, as well as reducing bias and discrimination and health data algorithms. Goal 4 is a more infrastructure-based goal. The objectives here are really about





building or continuing to build on infrastructure and health IT capabilities. The first objective is development and use of health IT capabilities continues to advance. Capabilities include things such as continued increase in adoption and use, increase in reportability and, of course, more usability. We are also focusing on health equity by design, as we will talk about more later.

Health IT users have clear and shared expectations for data sharing. The big one here, of course, is supporting a national exchange network, particularly TEFCA is noted but also, just promoting the knowledge and understanding about health data exchange ensuring that that knowledge is shared and that people can understand the issues around data sharing and when it is safe and private to share. Underserved communities and populations have access to infrastructure that supports health IT use. The strategies are focused around expanding our broadband infrastructure to reach areas that are currently underserved and to ensure that the flow of electronic information there is smooth and easy. Particularly the focus here is also to advance equitable access to affordable technology. We want to make sure that everybody can easily access their health information. And to do that, they will need the technology that is behind it. This objective is individuals' electronic information is protected, private, and secure.

This is something we mentioned throughout all of these is maintaining this. We want to support mechanisms for privacy and security. We also want to reduce privacy and security risks. And the final objective, although still very important, is communities are supported by modern and integrated US public health data systems and infrastructure. This is really the one that focuses on public health modernization, supporting the rapid exchange and use of public information to address hazards as they appear and, hopefully, before they appear. We really want to advance public health data science capabilities, as well as its overall capacity. Those are the goals and objectives and strategies for the strategic plan. I will quickly go over the appendices and then, we will have time for questions. When we were developing the plan, and Peter has covered several of these already, there are a few considerations that we really wanted to focus on as we develop the goals, objectives, and strategies.

Public health, as you have seen, is throughout. It has its own objective within Goal 4. But we have also tried to make sure that it was represented throughout. And that is the same case for all of these. You will see health equity throughout the strategic plan, artificial intelligence, increased use of health IT and electronic health information. Privacy and security is noted as much as we can because of how important it is. We also tried to identify some federal government use cases. And then finally, we really thought about the collaboration and coordination between both the public and private sectors. This slide focuses particularly on how ONC will measure progress. We will continue to note progress within this plan of the strategies within this plan through our congressional reports. The areas that ONC particularly focuses on is USCDI, USCDI+, the Certification Program, TEFCA, and general information sharing, as well as health IT alignment in the U.S. Department of Health and Human Services (HHS).

Again, this is our request for feedback and we are reminding everyone that our public comment period ends on May 28 and we would appreciate not only your feedback, but if you could also reach out to your partners and colleagues and ask them to take a look at our plan and provide any feedback, that would be great. We also want to note that while ONC has been the one promoting this plan, the federal partners have had a significant role in developing this plan. We have worked very closely with them in identifying the strategies, objectives, and goals that really get to the heart of the work that they are doing and tried to make sure that they were all represented here. You can see our federal contributors and many of the agencies that





participated in our process for developing this plan. That is everything for the Federal Health IT Strategic Plan overview and thank you all very much. I think we are opening up for questions.

Medell Briggs-Malonson

Yes, we are. Thank you so much, Peter and Dustin, for an amazing presentation. The strategic plan is very thoughtful and brings in so many other different elements that we absolutely need in order to advance health IT. The chat has been really on fire with robust conversations. And I would ask all the HITAC members at this time, if you do have a question or comment to please raise your emoji hand. We will also go through some of the chat so we can bring up some of your ideas as well. I first see Bryant's hand.

Bryant Thomas Karras

A quick clarification. Thank you so much. Fabulous presentation to the both of you. The contributors from HHS as one of the shields that you put forward is a very broad department. Is there any detail in terms of the sub contributors, Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), and others that may have had more focused contributions? And I am assuming that if the Secretary of HHS has signed off on the strategic plan that the directors of each of the sub cabinet members of the HHS are also signed on.

Peter Karras

This is Peter. When we went through the plan development process, we had several rounds of goal workgroup meetings. What is listed on the slide in terms of the components is at a higher level. You are correct in that we are not including with the subcomponents. I think there is an opportunity for us to get to the level of below the department, the specific agencies within the department. We listed, from a formatting perspective, the operating divisions and staffing divisions rolled up into departments. I think there is definitely room and further communication or even with the strategic plan to drill down to the specific components. These departments and organizations all participated in the plan's development process. And it is a point to just emphasize that this is not an ONC plan. It is not an HHS plan. It is a Federal plan. I definitely wanted to make that point. And that slide is really trying to get to the federal contributors. Thanks for that note.

Bryant Thomas Karras

Thank you. And I think a plan is as good as its adoption. I would love to see it cascading into each of the member organizations that we work with directly. Thank you so much.

Medell Briggs-Malonson

Thank you for that question. And thank you, Peter. Michael, you are up next.

Michael Chiang

Peter, awesome presentation and work putting this together. I took some notes about things and maybe I will send this by email. But I just wanted to call out a couple of them that might be worthy of discussion. One of them is clinical workflows. I think it was Slide No. 13. I think that that row implies that HIT should support clinical workflow or that HIT is supporting clinical workflow. But I believe the reality is that often clinical workflows have adopted to support the limitations of HIT. This includes things like copy-paste, scribes, and text templates that make all notes look the same. I wonder if you would consider a statement that HIT needs to improve to support optimal clinical workflows in an iterative way.





Along those lines, I really had to endorse Keith's comment about data quality because I think this is in the research bullet point or I guess it is No. 3 that one huge problem is really poor quality of the EHR data. Billing codes or diagnosis codes are often inaccurate, and medication lists and problem lists are often outdated. And large-scale administrative datasets, registries, etc. are often populated based on billing codes. We have seen this quite a bit, as I think everybody has. And I would definitely agree that this would benefit from just being called out: the importance of data quality.

There were a couple of other items that you mentioned like quality and price. I think it was Slides 15 and 16. Probably to also say what is obvious, I think there is a challenge in measuring quality. The quality measurements that we have, the clinical quality measures (CQMs), it is all of the obvious concerns that we have probably all heard a million times. They do not always normalize for complexity of care and may therefore bias against clinicians who care for underserved or otherwise complicated populations. And some of the CQMs are so easy that "high quality versus low cost" really means low cost because everybody gets maxed out on the "high-quality" component of the CQM.

I just wonder if it is worth specifically calling out and sharing that we need to develop good ways to measure quality. And I am sorry to go so long on this, but some CQMs that we've examined are just not always computable: it feels that they were written for an era of manual chart abstraction from paper charts. Even when CQMs have algorithms for how to compute them, what we've found is that different people often interpret those algorithms differently and therefore calculate different numbers based on the same quality measures. We need to be more precise in defining CQMs and specifically how to calculate them.

I think this is really an awesome piece of work from you.

Peter Karras

I appreciate that. Thank you so much, Michael. I definitely did see a lot of emphasis on data quality and the need to incorporate that in aspects of the plan. We do talk about data management, data governance, and provenance. And I think there is a recognition that we are focusing on interoperability and trying to move clinical data, but also there is an aspect of the metadata that is contributing to data management and quality in terms of who created it and when was it modified and how that moves along as well. And I think that is really important for a patient to understand and to really help in their care delivery and journey. It is important to know what your allergy list is but also important to know when did you get that allergy and who modified that list and was there anything else going on at that time that could maybe have contributed to it? I think that is a focus, too. I appreciate the comment.

Medell Briggs-Malonson

Thank you so much, Michael, for all of the important comments that you provided. And thank you, Peter. Dan, I see your hand.

Dan Riskin

Thank you so much and I will take my hand down. First, Peter, I will add my congratulations. This is a great piece of work and well presented. Thank you. I wanted to follow onto the data quality question. I know there has been a lot of mention of EHR. But we are seeing data quality problems across the landscape. We are seeing problems for primary use, secondary use, and now popular in the news is artificial intelligence as a





secondary use of health data. Is the intent in this effort to hit EHR, or is the intent to hit health data as it goes through the continuum across different systems and for primary and secondary use?

Peter Karras

It is both. We can acknowledge that Health Insurance Portability and Accountability Act (HIPAA) protections, while broad, are not necessarily absolute. There is a lot of tension between information that is getting pulled out from the EHR and looking at the terms and agreements and where most consumers fail to really understand the secondary uses of data and how that is being dispersed. A lot of times, you see a patient or consumer at the mercy of a provider with these secondary uses of data. And I think it is a concern because most apps outside of EHR are collecting data. They are using data. They are selling data. From a privacy standpoint, I think there is technical nuances, but there is also some policy and educational components. And part of that within privacy and security, there is multifactor authentication and making sure that folks who have the secondary uses of data are using it in an adequate way. A part of it is in education. I think it is important when you look at privacy and security, there is only so much that we can do in the current landscape when you look at where HIPAA is and what is happening outside of it.

I think education, which is the focus we try to put in is look at the terms and conditions. Try to understand a lot of developers can change these terms and conditions on a whim whenever they want. And you are forced to just download and reinstall the app and accept the terms. I think education and knowledge is power. How your data is being used, understanding who is collecting it, what they are doing with it from at least an educational policy standpoint is something we also try to address.

Medell Briggs-Malonson

Anna, you are up next.

Anna McCollister

Thank you so much for this. There is so many things about this presentation that I think are really good and helpful. I love the fact that you began with the focus on individual access and empowerment and being able to use the data to manage one's own health and care. I think that is essential and frequently, again, the role I play here on this committee is as a patient. So much of what government focuses on is providers. Thank you for that focus. I have a number of questions. One of my big questions is does ONC currently have statutory authority to do all of this? Or does some of this begin with what needs to happen and then, hopefully, Congress will step to the plate with additional capabilities or statutory authority or funding, etc.? And then, I have other thoughts specifically around equality and the concerns about that. But I think others have already articulated some of those concerns.

Peter Karras

It was a great question on authority. There are a couple of things with that. It is a federal plan so it is not necessarily just ONC. What we are communicating I look at it as a mosaic or puzzle. Different agencies see themselves in the plan and the work that they do. That helps contribute to the overall achievement and the accomplishments. Everyone is a piece of the puzzle. And then, in terms of just the way it is written, it is written in a way where we actually try to make it tool agnostic or program agnostic or authority agnostic in a way where we recognize there is multiple ways to the way. When we talk about empowering patients or empowering patients with access to health information, we do not want to specify in such a way where it





might be through one regulatory action where now you are updating specific certification criteria where you can have patient service Application Programming Interfaces (APIs) are able to access that information.

I think it is part of the process and us taking a more broad approach in recognizing that it is not just ONC. And there are multiple ways. It is kind of just describing an outcome and a goal that we are trying to achieve within the confines of what our federal agencies and federal partners work towards and the way that they serve their target audiences as regulators, as purchasers of health IT, as providers and users of health IT. So, to try to run through that gambit.

Anna McCollister

Should I assume based off your response that you did begin with what statutory authority exists across all HHS agencies and considered the vision, the direction within a context of what authority already exists? It is not like this is going to require additional legislation to be able to meet these goals?

Peter Karras

We went through the process with our federal partners understanding their specific programs and areas of influence and spirit of influence and control when we crafted the plan and when we cleared the plan. That is a safe assumption in terms of what you are describing with statutory authority.

Medell Briggs-Malonson

Thank you, Anna, for that question of clarification. And, Peter, that is wonderful news as well. Keith, you are up next.

Keith Campbell

Good morning. There has been some discussion of quality. And I just want to point out a strategic thing we can try to do to make sure that the need for quality and the understanding of the need for quality is well communicated. When I read the report, I found many areas of the report that could imply the need for data quality. But I was challenged to find a specific call out for data quality. And when this committee was previously presented, TEFCA, we discussed the need for trusted data exchange to incorporate trust in the data quality. At that point, the presenters responded that there was an assumption that if the standards were followed, if you use FHIR, that quality would be present. And many on the committee at that time asserted that the standards were necessary, but they were not sufficient to get the quality goal attained that we need. My counsel, I guess, is that we just need to be very specific about calling out things like data quality and not assuming that at a higher level, they will just be managed in some specific way. Thank you and I appreciate all of the other comments that people have made about data quality.

Peter Karras

Thank you.

Medell Briggs-Malonson

Thank you as well, Keith, for pulling that out as well in this conversation. Mark?

Mark Sendak

Hello. Thank you for the presentation. This is super helpful and I will probably send more detailed notes in an email follow-up. Building on Anna's comment for my first point, a plan like this because it is federal





government and crosses multiple agencies, it would be helpful to explicitly call out what the white spaces are and how those will be filled related to statutory authority. For example, Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing (HTI-1) is great legislation. It is a great final rule. The limitations of it are the third-party algorithms that are not distributed through EHR systems are not affected. The other example that I have explicitly is patients interacting directly with AI systems. This could be Chat GPT. This could be other systems that they can just get a hold of and use directly. There is no transparency requirement for use of what we think of as health technologies but that are not in the EHR. Making explicit federal government intention to expand the statutory authority to cover these uses of health IT that currently are not affected by whatever great work being done.

The other piece, and this is for me particularly grounded in experience from other work, the framing of Page 21, this is Goal 3 Objective C, the title of the slide is Researchers Advance Health Equity By Using Health Data That Includes Underrepresented Groups. I find the framing troublesome. And once again, this stems from I was part of a very large National Institutes of Health (NIH) program that was meant to advance the use of artificial intelligence (AI) to promote health equity. One of the outcomes of that program was transferring large amounts of data from marginalized communities to an enclave at an ivory tower institution in the northeast. And I would say there were many communities that felt this was an extractive effort to advance the access of data from underrepresented groups for the same types of researchers who are used to doing this type of research. I would pose a challenge to try to get us to rethink this in terms of how do we promote research within underrepresented groups so that they themselves are not just able to do the research but execute the research and drive changes in clinical practice using their own data.

I have seen and I think we should be worried about extractive efforts that move data into the hands of well-resourced researchers from underrepresented groups. I just wanted to call that out.

Peter Karras

Mark, just so I am clear, you are making the distinction between the data set itself and the folks doing the research.

Mark Sendak

Yes. It is important who is doing the research and where the data is coming from because I think we have been focusing too long on curating research from marginalized groups. But then, the folks working with the data are not from the marginalized communities.

Peter Karras

Thank you for that point.

Medell Briggs-Malonson

Mark, thank you so much for that point. I fully agree. One of the important pieces about data justice, what I always like to say is the data of the people belongs to the people. And we have to continue to support that and curate that because the interpretations of data from various different groups is best often interpreted by those in which the data comes from. Thank you for that.

Mark Sendak





And the benefits of the research.

Medell Briggs-Malonson

Correct. Thank you, Mark and thank you so much, Peter. Hung, you are up next.

Hung Luu

First of all, I want to congratulate you on that excellent work. It really shows why the ONC needed to be created. It really employs a holistic approach that tries to break down silos and incorporate strategy that can be utilized across the government agencies and the healthcare ecosystem. I do want to, again, stress the need for data quality at the point of origination. It is, obviously, important that the data is represented adequately so it can be understood by the end user. I also want to stress that the transmission of that data through the different standards can be corrupted by the use of different versions. And I do understand that the strategic plan intentionally is not prescriptive. And there are no implementation plans in there. But I think at the very least, maybe an investigation of how the adoption of different versions of standards impacts the data quality needs to be undertaken because I think that would highlight and maybe not require, but at least help to highlight the importance of limiting optionality.

And that happens when different versions of the same standard are employed by different agencies and different institutions because everyone assumes that they are receiving what the sending organization intended. But if the standards are different and the receiver is not receiving it in the correct order or in the fields that they are expecting, information can be shaved off. And then, it is no longer useful because you have lost so much of the original meaning.

Medell Briggs-Malonson

Peter, any thoughts about that or agreement with that?

Peter Karras

I definitely agree and echo that sentiment. I appreciate all the points just generally from the committee on data quality and the need to look at ways to emphasize or spotlight that in the plan. It is part of why we have it for public comment and we take it to the HITAC to look at. I appreciate everyone's comments and thoughtfulness in their review.

Medell Briggs-Malonson

Thank you so much. Michael, I see your hand but I also see Hannah's. If you do not mind, I am going to go to Hannah because she has not had a chance yet, and I will come right back to you. Hannah, we will go ahead and start with you.

Hannah Galvin

Thank you, Peter and everyone who worked on this. It is a really fantastic and thoughtful strategic plan. As a Chief Medical Information Officer (CMIO) of a safety net organization, I want to represent the population that I serve. And I think this plan is really comprehensive and I do see on Page 9 and I really wanted to call out the need to expand access to smartphones and other connected technologies. There is a real need to also expand broadband internet as well, both in rural areas and where I practice in urban areas as well and public housing. I think I wanted to point out that as we are innovating and AI is really taking off and there is a lot of innovation, there is a floor as well. And there are a great number of Americans who do not have





access to basic health IT and broadband. I would love to see this plan even call out a little bit more a strategy for all Americans to achieve that floor as we continue to innovate. And, of course, all of the things we discussed around data quality are essential as well but really having a plan for all Americans to achieve that floor is really what I wanted to call it. But excellent work and thank you for all of the efforts.

Peter Karras

I appreciate that, Hannah. Thank you so much for that. I definitely agree with the importance of that infrastructure. And I recognize that it is a huge challenge. And sometimes it is lost on a lot of folks. But there is the need to really ensure that folks are able to have the tools to participate along this journey. And a huge part of that is broadband and connectivity. And I completely agree. That is part of equity as well is we do not want those in specific communities left out. And I think that infrastructure piece and even really the hardware components that are necessary to supplement or support the software that we talk so much about, it is vital. Thank you.

Hannah Galvin

Thank you.

Medell Briggs-Malonson

Thank you, Hannah and Peter. Since we are talking about inclusivity, one of the other pieces about digital divide is yes, it is as we mentioned, the IT infrastructure as well as the hardware. But there is also the digital literacy. That is also a very important piece to call out and think about in order to ensure that everyone is able to use the technology appropriately. And it is also very inclusive in terms of languages and adjusting for those who have various diverse abilities, whether they are physical various different abilities or cognitive. Thank you so much for that. Michael, I will go to you next and then, Rochelle.

Michael Chiang

Thanks, Medell. I just had two other comments that I thought it would raise. One of them is on Page 20. Peter had a bullet point about protecting deidentified health information from re-identification. I just had a little concern about that because it did not totally make sense: if data are deidentified, then, by definition, they cannot be re-identified. It just called into question some deeper questions about whether this term of “deidentification” is really a misnomer. Is it a true definition or is it a legal definition? I wonder if that would benefit from being rephrased a little bit.

And Page 17 called out education. I just wanted to suggest that this is a huge, important topic. I would argue that HIT is the only tool that is used by every single clinician in this country. Yet, people do not really get systematic education in it. We kind of learn it by trial and error. I just do not think a lecture or a short course is enough to really move us forward. And I would just suggest that we may need education on health IT will need to be really deeply embedded into the medical education system. We'll need future generations of clinicians that think of HIT as being fully integrated into the practice of medicine and who understand its benefits and limitations.

Peter Karras

Thank you, Michael. I wholeheartedly agree. We definitely try to call out the healthcare workforce and the ability to constantly use health IT. And health IT education and training programs are definitely something that we include in the plan and we want to make note of. I think that comes in all forms and how that is





embedded within specific institutions as part of training and formal education I think is always something to consider.

Medell Briggs-Malonson

Thank you. Rochelle?

Rochelle Prosser

I am traveling and so I will stay off camera. I just wanted to say thank you for your leadership. You stole my thunder on the education [inaudible] [01:05:53]. But I also wanted to talk about the health data and another case example of where an institution is [inaudible] [01:06:03] and we clearly do not know the indication of what the use is because they are not traditionally the ones asking for this quality of data. We want to be mindful, or at least [inaudible] [01:06:20] or be cognizant of that as we look to collect data and the nature that their privacy is there but also, is the intent to ensure that we are not exactly [inaudible] [01:06:39] for the targeted populations. As we look at our USCDI [inaudible] [01:06:45] summit and other agencies that are promoting and helping to socialize what we are doing here on the HITAC, we also want to make sure that we are instructing and educating.

Just because we can [inaudible] [01:07:05] our data, we need to make sure that we are asking for it with a purpose and intended guidance to make sure that we are not doing harm. Just be cognizant on that and promote the health equity directives that we have. It is easy for larger institutions to say, "We do not have this data. Let us go ahead and look at that." But is that the best use? We want to make sure that we are aligning with people who are in the population that should have first look at that data [inaudible] [01:07:39].

Medell Briggs-Malonson

We missed you a little bit on the end but I think we received it all. Peter, any thoughts?

Peter Karras

I agree. I think that is something that we touch on in the plan and that we should continue to focus on the use of the data in a way that the patient or consumer understands how it is being used and how it is being collected. And then also, getting to a point where there is education on the terms and conditions and the understanding of the service provider and what they are doing with it. And I think that goes a large part into how we educate and what we can provide so the burden is not always on the patient or consumer but how to make those things as easy as possible acknowledging that there, obviously, are constraints, especially when we are outside of the covered entities.

Medell Briggs-Malonson

Thank you. Anna?

Anna McCollister

Thanks again for coming back to me. Part of what I am trying to get my head around is that there are a lot of really good things in here, not just about individual access. I am a big proponent of using secondary data for research. I am a big proponent of using good, secondary data AI as long as we can have good data quality, which I am a little skeptical about it at this point but, hopefully, we will get there. My question is that there are some really basic things that ONC has been working on for quite some time, such as patient access to data in their portal that are not being done. Different providers will have an EHR that ostensibly





does it. But if you go to your patient portal, you cannot get access to your data. The providers in some cases say, "We do not really use the patient portal. We have one because we have to have one."

Part of my question and my concern is the same thing with education. Yes, we need to have more education around all the stuff. ONC has one really good person to deal with consumer education and consumer outreach. She is awesome but she is one person. My question is does ONC and do the other federal agencies that are represented in this plan have the A). statutory authority, which you said they do, B). any kind of enforcement capability to be able to go after people who are not complying or who are obstructing these kinds of actions, and C). do you have the budget to be able to do this kind of thing? Or is this meant to be our vision and this is what you are going to take to Congress or the Secretary of HHS is going to take to Congress and say, "If you want this to happen, these is how it is going to be funded?" Again, part of my comments are based on the fact that I think this is a really good strategic vision and plan. Kudos to everyone involved for that.

But as an advocate, I want to know what exactly it is we need to do as patients and community as the broader health IT ecosystem to give the government the ability to actually do this as opposed to just put together a really good plan.

Peter Karras

Great points. A couple of things on the statutory authority piece. Within statutory authority, there are things that we could accomplish. But I do not want to give the impression that it is the only way. When we looked at the plan and we met with our federal partners and we went through goal workgroup meetings, it is run in a way where we are trying to get to an outcome. There are programs. There are specific levers that federal partners are working on that they are planning to work on that could supplement trying to get to the outcomes in the plan. Of course, statutory authority and the levers, as an example within ONC what we do with our Certification Program, that is a capability in the same way other federal agencies use their statutory authority to accomplish their goals. But it is a vehicle but I do not want to give the impression that it is the only way. There are other mechanisms to get to where we are trying to go. And yes, it might require more funding. It might require potentially increase in budget. But this is meant to be a definition of an end state that we are trying to reach to meet our evolving needs in our ecosystem.

Are there going to be gaps along the way? Potentially. I think those are things that we constantly need to note. But this is a plan that is meant to align the organization. And there is a point, I think I saw in the comments, of how the plan is used. What we have seen with use cases is we have specific federal partners like the United States Department of Defense (DOD) and the Veterans Affairs (VA) and the firm who actually take the plan and use it and the goals and objectives to align their own work and their programs, too, as a way to move in one collective direction. That is the intent. The strategic implementation is something that we continue to monitor. We do want to track to see what are the programs, what are the projects, what are the efforts, whether that is within a statutory authority or not that are at least trying to get to, ultimately, promoting health and wellness, enhancing the delivery and experience of care, how our research efforts are being advanced. Statutory authority is a mechanism but it is not written in such a way where that is the only way to get to where we are trying to go.

Medell Briggs-Malonson





We have about five minutes left for the session. Are there any other questions or comments from HITAC for Peter or Dustin? I am not seeing any. I do not see any other movement in the chat. This has been such an amazing, robust conversation and so informative. Peter and Dustin, thank you so much for presenting to this. And we hope were able to provide some of our input and our feedback. And we look forward to the next steps. Thank you so much.

Peter Karras

Thank you. I really appreciate it.

Medell Briggs-Malonson

We appreciate you as well. Now what we are going to do is transition into the next session for the day. Our next session is actually going to be led by Leonie Misquitta. And she is going to lead us through the USCDI+ for Maternal Health.

USCDI+ Maternal Health (01:15:05)

Leonie Misquitta

Good morning, everyone. And thank you for your time today to talk about USCDI+ Maternal Health Initiative.

Medell Briggs-Malonson

One moment. We are having a little bit of problems with your audio.

Leonie Misquitta

How about now? Is that better?

Medell Briggs-Malonson

That is better. We will if we can adjust your volume. It is much clearer. Maybe a little bit louder and then, we can hear you just fine.

Leonie Misquitta

Can you hear me now clearly?

Medell Briggs-Malonson

Still a little bit of an echo there. We are going to try to see if we can increase your volume on our side as well. But you just sound a little bit further away. Maybe a little closer to the microphone.

Leonie Misquitta

Sometimes Zoom does this and I have tried everything to fix it.

Medell Briggs-Malonson

That definitely sounds better, thank you.

Leonie Misquitta

Sorry about the start. Thank you again for your time. I am Leonie Misquitta. And I lead this work in the Networks and Scalability Division within the Office of Technology at ONC. Can I have the next slide please?





Why is it important to have a national standardized maternal health data set? And to understand the need for the national standardized data set, we need to look at the data for the maternal morbidity and mortality rates within the United States. And among our peers in the developed world, the United States performs really badly in averting maternal mortality almost at the rate of more than double that of our high income peers. If you look at the data itself, there are a few categories of the data, but almost one-third of the data of these percentages of deaths really occurred during pregnancy. And a majority of the rest of the two-thirds of the deaths occurred within from delivery to more than 42 days postpartum. It is kind of a high rate.

Now, if you continue to look at the data from across populations, we see an even more significant disparity in pregnancy related mortality and morbidity rates across racial and ethnic groups. Research indicates that as much as two-thirds of pregnancy related deaths are preventable. There are key factors that actually contribute to high mortality and morbidity and that includes variation in clinical practice patterns, access to care, and data limitations in quality, which has been brought up in the previous conversation as well that really innovate an exchange of data and also research related to these fields. What we are focusing on really is the last of these key factors and that is the data limitations to address these gaps by creating this national standardized maternal health data set so that we can address the capacity, interoperability, coordination, and access.

As we were looking at addressing these gaps in maternal health, there has also been a recent coalescing or focus or meeting of minds across communities and across agencies to make improvements in the health outcomes of pregnant and birthing people and to make maternal health a national priority. This is also reflected in current and previous administrations and national maternal health initiatives, some of which are highlighted here. ONC is part of the larger efforts that are being led across HHS, but also specific initiatives to maternal health, in particular the USCDI+ maternal health effort that we have been talking about. In parallel, ONC is also leading pilot testing to identify needs and capabilities related to the access of maternal health information. If these gaps are not addressed, it results in critical health information either being unavailable or nonexistent, especially within this maternal health domain. To focus on maternal health, what we are doing is building out on adopted standards using USCDI to support the data capacity, interoperability exchange, and sharing of data so that it actually provides for better outcomes in maternal care.

Most everybody on this call is very familiar with USCDI. It is a very impactful model and framework that has been used across the board. But what USCDI+ really is doing is it is both an extension, as well as a complement to USCDI. The maternal health was identified as an area of focus. And, therefore, we are using USCDI+ as a model to increase and to develop data sets for maternal health. This is also done with the intent on bringing to light the data needs across and outside of HHS in specified areas, maternal health being a very key focus right now so that our partners that collect and exchange data can have a data standards guide to reference when they are thinking about exchange and analysis of data. Now, we have worked with a number of agencies in the past year or so on maternal health to advance the development of the USCDI+ maternal health data set, CDC, CMS, and NIH in particular. We have partnered with the National Institutes of Health to work further on it as well as the consortium.

And while we were focused on establishing this core set of data, we focused on a few things. We wanted to focus data that is necessary for high quality care, for equitable outcomes, and maternal health research. The intent is to iterate this data set over time expanding it as needed, conducting pilot studies, conducting performance testing, and to eventually see an option on the large scale. While we were initially thinking





about our inclusion and exclusion considerations for this current draft USCDI+ maternal health data set, we grouped them into three key areas. The importance of promoting high quality care and addressing gaps. Basically, the question is, is the data element likely to contribute to high quality equitable care? The next one would be the likelihood of data availability through routine documentation? There again, the question really is how hard is it to collect data during your routine workflow? And that one really is the implementation burden.

And the implementation burden really is the questions there would be will the electronic extraction and exchange of data require significant development of time to implement in health IT systems? This is really important in terms of getting adoption. And that has been brought up previously as well, and to have a data set that is robust enough to meet the needs of partners from the onset. Here are some of the priority areas that we considered in our analysis of the inputs. And we use this as a guide for the inclusion of data elements of the draft data set. And we acknowledge that, as we said, the data set will evolve, but they include elements that are related to inequitable or equitable treatment, timely access to treatment, risk appropriate care, and teams of substance use, mental health, and behavioral health. We also use the five goals from the White House blueprint, which I mentioned earlier on from the initiatives, for addressing the maternal health crisis as a guide.

Of note, Goal 3 is aligning very well with our work in USCDI. Goal 3 talks about advancing data collection, standardization, transparency, research, and analysis. And it also recognizes the gaps in data related maternal health and the need for consistent data collection and for standardization of data definitions. What we are trying to do here is with addressing these gaps of capacity, interoperability, coordination, quality, and access, we want to be able to build a reference that delivers high quality, maternal care. Now, moving forward in our work, our next steps really are to create or expand our data set. We have received **[inaudible]** **[01:25:10]** trust fund, patient centers outcome research to extend the data set to be more comprehensive so that it serves as the main reference for maternal health data and to provide guidance for standardized data collection and recording and exchange. What we would also have available in the next few months is the data set for public comment.

We are soliciting and we would like to receive feedback across the large spectrum from researchers, clinicians, public health leaders, tech developers, and industry at large on these data elements so that we can look to standardize this reference set to support high quality, respectful, and equitable maternal health care. We are working to move this work forward so that it will have an impact at the end of the day on the patient itself and maternal care so that there is a reduction bias, discrimination, access to care, respect for care, and so on. We can be reached by multiple ways. And we definitely appreciate all of the engagement. I am going to stop here. Thank you, again, for your time today. And I will hand it back to the co-chairs.

Sarah DeSilvey

Thank you so much for this presentation. It makes me a little bit emotional. It is such a crisis that the status that is addressing certainly within my critical practice hat and my director of terminology at Gravity Project hat and then, recently co-chairing IS WG where we elevated the maternal Social determinants of health (SDOH) note as a hopeful data element. It is a very pressing topic. And thank you so much for ONC and Leonie for this presentation. It is now my honor to go to questions. There are some questions in the chat. I am going to focus first on my amazing co-chair, Medell. A question for ONC for this topic.



**Medell Briggs-Malonson**

Thank you, Sarah, for that and I share your passion in this area. And thank you, Leonie. I share this passion in this area, not only due to my own personal birthing story, but also seeing so many aspects that have continued to occur in our country for decades. And I am currently leading maternal health efforts, not only here at UCLA Health, but throughout the University of California Health System, in order for us to directly address racial, as well as socioeconomic inequities when it comes to overall morbidity. And so, Leonie, I am very happy that you brought up the fact that we are really looking at severe maternal morbidity because what we do know is that mortality tends to be a relatively rare outcome. However, when it comes to severe maternal morbidity, it is much more common. And those are the elements that actually do lead to mortality. In a lot of our health equity work we are doing right now, we are actually focused on Severe Maternal Morbidity (SMM) and identifying those various conditions and trying to mitigate them.

But part of this actually involves really looking at all of the factors among the entire continuum of perinatal care and status, even from pre-pregnancy all the way, of course, up to a year after delivery in order to try to support the women as well as the birthing individuals. But my question that I wanted to bring up is that during my work right now, I have actually been working very closely with both commercial health plans as well as Medicaid health plans because in order to provide wraparound, comprehensive services, in order to try to mitigate some of the negative outcomes that occur during pregnancy as well as after delivery, we need to have partnerships with community-based organizations, health plans, public health agencies, as well as our healthcare delivery systems. And one of the primary barriers that we are experiencing right now with the health plans is that the data from our health systems do not flow to the health plans nor vice versa.

There is no interoperability. Also, the various different elements we are collecting, which we know can contribute to poor health outcomes, they also do not exist in a standardized way. Health plans go to billing and then, they go to other aspects and they finally get back to the people that are trying to provide those comprehensive services. My question is where are we with also, when we are thinking about interoperability, we are thinking about the standardization of all of these various different standards and elements that we are collecting, where do the health plans sit in the ecosystem? And if they do not sit in the ecosystem right now, I really think that that is another place that we do need to focus our efforts on, as well as so many others that we know are incredibly essential to this work.

Leonie Misquitta

You brought up a point that has been raised by [inaudible] [01:30:29]. This group is part of it and we are talking with many communities across the board and that includes health plans. And in my previous life, I have seen the same thing. There is very little interoperability, very little sharing of data that happens between this. We are talking with them. Part of the goal for public comment is to also add more data and data elements that individuals, communities, health systems, health plans, think would be useful to capture. I am passionate about this. But it is a matter of saying how can we capture the minimum number of elements that provides the maximum number of benefit across the board? If you put a huge amount of implementation burden, if you say you have 250 things to be able to capture on, you are going to have less intent of adoption. And so, we want to capture the most important and we have got some already in the data set that addresses some of your questions.

But I think it is very important when it opens up for public comment. We have had a couple of health systems and health plans that we have also spoken with very recently who have said, "We do not see this." We have





had some inclusions across it because, as it has been mentioned from the beginning of the call, quality is not just an issue but sometimes it just does not exist and the place you are expecting it to exist. EHR is a prime example of these. I have had lots of input from researchers and the clinicians that say, "We have to come up with proxy elements to even be able to calculate how the person has been given any therapeutics or any treatments." Once they are out of the hospital, it is difficult to follow because if they are in a rural area, they go to their primary physician. They are not quite always using the health IT systems to share data. So, it is not available because these deaths are preventable, as all of us know here, if this data had been available.

To answer your question, absolutely. And we would love to get feedback and input on these data elements that say that these are the key, these are the core that we need to do that actually benefits the patient across the board.

Sarah DeSilvey

Thank you so much for your question, Medell, and for your response, Leonie. One of the things I want to elevate here, and it goes back to some of the conversations we were having on the strategic plan, is the importance of making sure that we disseminate this opportunity for public comment to the entities that we know are experts in the community that are not often centered in these solutions. I think about the people and leaders and experts I have had the honor of working with at the Gravity Project. All of us as HITAC members, in honor of the fact of the data, is the people. The experts are often not in the circles with us. I just want to embolden you to, once this is released for public comment, to make sure it is disseminated broadly and widely so we have the right people assisting ONC in this critical task. Katrina?

Katrina Miller Parrish

Just let me know if my bandwidth causes problems with audio or video. Thank you, again, for your presentation. This focus is so important. And I am going to dovetail on Medell's comments. I work with two health plans that had very different approaches to both interoperability and maternal care. If you have seen one health plan, you have seen one health plan. They have definitely different ways to focus on both of these different aspects. But I do think with all of the TEFCA requirements and information blocking requirements, we are moving to a better future state for interoperability for understanding more comprehensively the full clinical state, especially of the maternal health patients. What I want to focus on is something that I am sure Anna and Rochelle and others on this call would echo as well, and that is Goal No. 2 that you have on your slides, which is ensuring those giving birth are heard. I will just stop right there.

The No. 1 problem with most of the morbidity and mortality, as we all know, is that it is not by looking at the data to understand what is going on with the patient and the birthing person, but not listening to what they have going on. And then, not having appropriate either forms to be able to gather the information correctly, or consistent data elements to be able to capture that information. And so, I do hope in the USCDI+ maternal compendium that we focus on how to capture the patient's voice and then, the response to the patient issues in a timely and appropriate manner because just having a nurse respond and check a box to say, yes, I responded, is not enough when we are talking about hemorrhage and clot, PE and all the various things that can cause morbidity, like Medell was saying, and then progress to mortality. Luckily, rare but still egregious and horrible when it happens.





I am concerned that we are going to focus a little too much on current data that is available in just tracking the vital signs and responsiveness and American College of Obstetricians and Gynecologists (ACOG) forms and things like that. And we really need to come up with those quality values from the patient's voice that really allow us to address this issue. I hope I made that clear. And I know it is a complex issue. But I think we all agree and we just need to figure out how we will do that. I think USCDI+ could do this.

Leonie Misquitta

Exactly. You brought up one thing that we have heard but there is personal and lived experience within the group. And we actually have a data class that we are planning to also has input, which is on patient experience, respectful care. And what you are saying exactly, how have they heard how is that captured and how is that actually going to impact their care. I am sorry. I am repeating myself but this is where public comment is so important. And that is to say let your voice be heard so that we can actually capture what is important. We hear you and we have this already on the working draft. And it will be interesting to see what comments we get on it and how much more we can extend to capture it. That is a huge problem when it comes to care, in general, but maternal care in particular.

Sarah DeSilvey

Thank you so much for the response. It was nice to see that again in the additional use cases section and highlighted again by ONC. Ike?

Steven Eichner

Thank you so much for the great presentation. We were having a great conversation online and looking at data quality issues. One of the things that I am thinking about is how do we simplify the exchange of information for public health and care purposes so that we are not looking at duplicate or replicating activities for different purposes? And how do we incorporate the ideas and the elements that you have included in USCDI+ for maternal morbidity and mortality into greater data flow so that providers can use a single connection or single methodology for exchanging maternal morbidity and mortality information, whether the destination is public health or another healthcare provider or coordinating care? We are getting further away from special purpose exchange to better just general connectivity.

Do we look at trying to implement this as a FHIR protocol or something in that space where there is a FHIR resource, any library of elements that could support either or both but, again, still looking at those high quality data elements so that providers can leverage a single type of transaction for the different purposes?

Leonie Misquitta

Yes. I heard a few questions there, Steven. You bring up a good point about saying is there duplication across the board between the domains. We are trying not to have that kind of implementation burden for the adopters, to answer that question. The second question is that I briefly mentioned that we have a collaboration with the NICHD, which is the FHIR Implementation Guide for maternal health. And they are using that as part of a pilot to check and see what are the gaps and how it is being implemented, and how we could use that to have a more I do not want to say limited but a standard set that could be implemented without increasing the burden on the adopters.

Sarah DeSilvey

Thank you so much, Leonie. Ike, did that answer your question?



**Steven Eichner**

Yes. That was great. Thanks.

Sarah DeSilvey

Now onto Dayo.

Dayo Oshunkentan

Thank you for the presentation, Leonie. I wholeheartedly agree with all the commenters before me, such as Katrina, Medell, and Sarah. When I look at this subject, which is passionate to all of us as you can see, Leonie, I cannot help compare with other countries that have lower maternal morbidity and mortality rates like Norway and the Netherlands. And when I look at their model, it is bigger than health IT. I know we are here doing Health IT. This is our focus. But when you look at their model, it is the emphasis on the importance of midwifery and providing continuous care throughout pregnancy, as well as in the postpartum period. So much so as in providing home health visits. And I think we need to get back to the crux of medicine of the patient and the individual before we can even address some of the other contributing factors. Health IT certainly could be leveraged, in my opinion. But again, I think we need to look at the crux of what the issue is.

And Katrina hit it on the head because in a lot of the stories, the patients are not being heard. And I know that Medell shared her story at our last in person meeting and it just echoes that sentiment. I think the biggest thing right now that is in dire need is advocacy for these patients and women. On the flipside, when I sit back and look at it, I am on this committee. How can health IT help? I can only think about, at least in my limited view, in one way in terms of when the nurses do get these calls and they are checking boxes like Katrina alluded to earlier, if there is an algorithm that triggers them to escalate it and direct the patient towards a path of evaluation rather than, "Okay, we heard you and we will relate it to the doctor," a few hours later. Or, "Oh, those symptoms are to be expected." I think maybe in that regard, if we have an algorithm that escalates those concerns and gives the nurses additional clinical decision support in order to escalate those calls, I can see it being fruitful in those circumstances. But ideally, I think we need to get back to the heart of it. And that is listening, advocacy, and supporting. Thank you.

Leonie Misquitta

I do not disagree with you but if you look at our developed nation data, and I mentioned in the beginning, there is one key difference. They have a centralized health system. We do not. And so, part of recommending at least these standard data sets is to say, "Let us get close enough to exchanging the data," so that as you talked about, the nurses and midwives have access to that data. We have heard this many times from lived experience is, they did not hear what we were saying. We were telling them that we had high blood pressure and was feeling dizzy and it did not matter when it came down to the symptoms that they were having and not being heard. I completely agree. Larger conversations, I want to say probably not specifically at ONC but across agencies and communities at large, that are exactly talking about this. It is like how do we address the key issue in patient care, maternal care in this case?

I agree but I think it is still useful because we have heard this over and over again. There are silos and we are collecting data but we are not collecting data that is in any standardized format. It cannot be shared from the researches. We have heard this over and over again. We cannot get the standard set of data. This





will help in a few areas but definitely I do agree it would not go down to the absolute root cause of where we need to get back to the roots of the process itself.

Sarah DeSilvey

Thank you so much. I do want to note that my origin is a bedside nurse. I was a bedside pediatric nurse for a very long time. And I want to note that one of the things we had to do to address very similar concerns in family-based care is allow patients to call flags outside of the hark of normal reporting. It did not have to go through nursing, it did not have to go through any levels in order for a parent or caregiver to initiate rapid response. And I just think about how that relates to what Katrina was saying that sometimes the structures of communication in healthcare settings regarding data can actually complicate rapid response to patient driven concerns, whether it be in maternal health or in pediatric health, which is my area of expertise. So, thank you so much. On to Hannah.

Hannah Galvin

Thanks, Sarah, and thanks, Leonie, for this really strong work and really important work. I do want to just note that I have not reviewed in detail USCDI's maternal health but I think it is super important. I have reviewed in much more detail USCDI+ behavioral health. So, my comments are the emerging USCDI+ data sets in general. One thing that I noted in that sort of more detailed review was a couple of things. One that I put in the chat. And it was that I appreciate your comments around trying to better understand. My understanding is that it is supposed to be extensional but in some instances, there were some core elements at least for behavioral health that were reiterated in the USCDI+ grouping, which is a little confusing. But the other is that as we get more and more USCDI+ values with those elements, there is a risk potentially of some semantic overlap in the data elements because the categories may be different, but the actual labeling of the data elements may be similar, even though you guys do a great job of calling out the definitions.

But for instance, one that I call out is that there is a category about federal research and grants. And some of the data elements under that sound very similar or sound semantically similar to other core data elements. And I think in clinical practice or in implementation, it may be difficult for implementers or frontline staff to understand the difference between those data elements. And as we get more and more of these data elements, we talked significantly with the last presenter around data quality. We want to be very sort of crisp and clear that each of these is distinct. And I just wanted to call that out in general as we have increasing USCDI+ data sets. There may be some risks there for us to look at. I am so glad that especially these areas of maternal health and behavioral health are being called out as areas that really need focus and data elements to help support better care of those patients.

Leonie Misquitta

Hannah, just a quick comment on that. The USCDI+ group as a whole is looking to make sure that these data elements do not get duplicated across different domains. And we already have relationships added in. The data element might exist in another domain, but this is also used in if it is in behavioral health, it is also used maternal health. You are not duplicating the elements, which basically says we have the same element in two places. Which one do I end up using? This is an element. It is used in two places. Pick where to use it. We are working on it and I totally understand.

Hannah Galvin





I totally get it. And some of the ways the data may be used for research or for quality metrics and things like that and this group has to think about all of those, may be subtly different but also slightly overlapping with the ways that data is used operationally. And there could be potentially some overlap or confusion in the way the people look at the element there. I think that users and implementers of USCDI+ need to understand what the category, the element, and the definition in the distinction between how each element needs to be realized is my understanding. Please feel free to correct it.

Leonie Misquitta

Absolutely. The context is very important.

Sarah DeSilvey

Thank you, Hannah and Leonie. Bryant, I saw you had your hand up. Did you put it down?

Bryant Thomas Karras

I pulled it down in the interest of time. But I will make a quick emphasis. I really applaud this effort. I think that this is so critical and important. And these kinds of outcomes and I applaud that we focus on outcomes, not just mortality but morbidity as well. I do worry that it could lose its emphasis. It could lose its voice in that it gets billed as a USCDI+, and not a USCDI core. And I think we should keep re-examining that perhaps some of these data elements are so critical that they need to become core so that they are not considered optional and only for those who really care but should be something that we all care about. Thank you.

Leonie Misquitta

Thank you, Bryant. And that is a process. And if we want to go to the process of how critical data elements are included in the larger USCDI because USCDI's regulation, there is a whole process within ONC to do so. And so, we definitely keep your comments in mind about the critical data elements once we have gone through our process of public comments as well. I will stop there.

Sarah DeSilvey

And Bryant is a member of the interoperability standards work group. Many of us are in IS WG as well and willing and ready to help escalate things once they are tested in the USCDI+. Hans?

Hans Buitendijk

Thank you. I would like to add on and expand a little bit on Bryant's comments in the comment I made in the chat around the implementation plans and what kind of HIT to target because I think Bryant raises an interesting and important point. What data is important for USCDI? What data is important for USCDI+? We still have this ongoing question that the way that USCDI is used would have to be used by all certified software. And not all certified software may have a need based on specialization, the context, etc., in the area that they are in that it is relevant for them to capture this or other data. It is a general problem. It is not just a challenge for this area. I think I would encourage in that conversation the same questions that we have raised in the past that as we have these targeted capabilities that certain specialty systems have to have, that certain general purpose systems must have because they interact with that, but not other specialty systems or other HIT that we really understand this.

How are these data sets being used? And how do we ensure that the right HIT supports those capabilities and others are not encumbered by requirements. In this particular case, the example that comes up if you





talk specialty systems, maternal health in a geriatric setting, is that relevant to require those systems to support that and vice versa? I think that needs to be part of the thought process that in the end, we want to get all the electronic protected health information (EPHI) enabled by standard supports to communicate to exchange at structure level data, at viewing data, etc. But in all of that, we need to recognize the wide variety of HIT, not just EHRs, but even within EHRs, what the systems are. I am really curious how USCDI+, in general, is going to be thought of and how it is going to be implemented and not just defied. But how does it find its way into the relevant HIT? And striking that balance between USCDI that is truly at the core that is currently intended for every certified HIT, no matter what they are, to be supported.

There is still tension there that we need to work on. It does not change the importance of the data, it just is an implementation consideration on how we ensure the right HIT supports it.

Leonie Misquitta

I do not disagree with your comments. Interoperability implementation burden, which I briefly raised is an issue. There was a previous question that said what are the critical elements that need to be included in USCDI from USCDI+. That is a critical question that takes a little bit more thought and planning. And your point is well taken. There are conversations around these questions of burden and implementation and what should be within the system, how interoperable is it going to be depending on we talked about maternal health in this context. But there are the other ones, public health, behavioral health, there plenty of other domains. And that, again, goes back to what are our critical data elements that should be within the system? But also, the difference between some systems may not be geared towards a more specialty set of data.

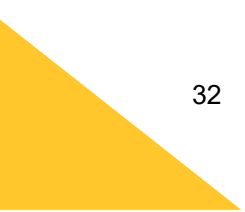
Sarah DeSilvey

Thank you. And I see Steve has his hand up. Steve?

Steve Posnack

I just wanted to jump in and add a little bit more context as well to Hans' question. And perhaps a reminder of a reorientation point for USCDI+ in general. I think everyone is well steeped in the USCDI. Let us call it Prime as a Transformers fan. But the USCDI+ initiatives are not necessarily one-for-one a regulatory pathway. And I think we have to recognize today that across the federal programs where we are now introducing a deliberate transparent, predictable approach for work to be done with the federal agencies, there is a wide range of discombobulated and uncoordinated data sets that the industry is dealing with today. And so, the USCDI+ process and using the phrase but not in any disrespect is bringing order to chaos from a data set perspective. And as we touched on earlier I think by Hannah, where there is overlap or synonyms or other types of semantic misalignment, that is surfacing in a much more clear and organized process now.

There are many different ways from an implementation perspective that USCDI+ data sets will come to life. Some could be through the regulatory process and certification. But that is not necessarily on the critical path for all of them. It could be through programs, related requirements, other types of funding that other federal agencies can provide. They can also generally be pushed out and used for coordinated industry effort like we have done with other public-private initiatives as well. I just wanted to highlight. I know you will get burdened with a lot of regulatory related inquiries. But this is a much broader coordination activity for us that goes far and beyond just the regulatory pathway. Thanks.



**Sarah DeSilvey**

Thanks so much. We are at time. My apologies. And if it is okay, if we can put any further comments in the chat so they can be captured as part of public comment. I do want to thank Leonie and ONC for this amazing work.

And I want to encourage everybody once it gets released for public comment to disseminate this dataset across all of the entities you know need to have comment on it. For break, we are going to pause the recording. The meeting will be kept live and we will resume the recording when we come back in 10 minutes. We will reconvene at 12:10. And again, Leonie, thank you so much for the presentation of this critical work. Thank you will members of HITAC for your very important questions. And thank you for ONC for the forum to have this conversation. We will be back in 10 minutes.

Seth Pazinski

Thank you, everyone. I am going to turn it over to Medell to take us into our next agenda topic.

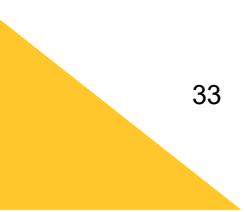
Advancing Health Equity by Design and Health Information Technology (02:00:51)**Medell Briggs-Malonson**

Thank you so much and welcome back, everyone. I hope you had a nice 10-minute break in order to grab a snack and some water. We have had already an amazing morning with so many different conversations about important topics. Now, we are going to end our session with an equally important topic and something that is also very near and dear to my heart, which is advancing health equity by design and health information technology. It is my pleasure to introduce Thomas Mason, our Chief Medical Officer from ONC in order to walk us through the advancing health equity by design process and paper.

Thomas Mason

Thank you so much, Medell. For those of you who do not know me, I am Dr. Tom Mason. I am an internal medicine physician and primary care provider. Prior to joining ONC, I worked caring for underserved communities on the south side of Chicago. In addition to my work, I focused on the adoption, implementation, and optimization of electronic health records, my passion for advancing health equity started early in my career. I was the medical director of a community-based public health intervention designed to target health disparities impacting black men in Chicago by addressing the social drivers of health and building trust with my patients and the community. Part of our approach was to abandon the traditional medical model and utilize innovative methods to build trust. We embraced a holistic approach to health and had social workers on the care team working side-by-side with physicians. We also had a barber that was a part of our care team that cut hair for free.

He was a health educator and really helped you make connections to either the physicians, social workers, or other services that were needed. I mentioned my background to convey my personal passion and dedication to advanced health equity. And I am really happy that health equity has been a priority of HHS and our National Coordinator, Micky Tripathi. ONC appreciates the opportunity to continue our engagement with the HITAC around this critically important topic. Health equity by design focuses on the need to include health equity as a core principle during the design, build, and implementation of health IT policies, programs, projects, and workflows. Health equity by design uses health IT to move data into action by using standards to identify and reduce inequities to achieve greater health outcomes for all individuals and





communities. ONC considers health equity by design in its policy development to support patients, clinicians, developers, and other partners across the health ecosystem.

The HITAC has already provided helpful insight and recommendations to advance ONC's health equity by design work. It was great to see last month the public hearing that the HITAC hosted focused on artificial intelligence. That hearing included a rich panel discussion on how equity principles can translate into implementation. And in March of 2022, the HITAC hosted a public hearing that explored equity considerations and health IT. And that hearing helped to inform the recently released ONC concept paper last month. At this point, ONC is seeking public feedback on the concept paper through June 10. It is available on our website. We are looking forward to the HITAC discussion today, which will be facilitated by Medell to allow for an opportunity for you to provide some of your insights.

The purpose of the paper is displayed. We are looking to identify how healthcare systems, public health agencies, clinicians, hospitals, and others within the health industry, developers are currently thinking about incorporating health equity principles and actions into their health IT design, development, deployment, analytics, policies, and workflows. We are looking to determine how ONC can best support and advance health equity by design in health IT nationwide through standards, policies, programs, as well as our coordination efforts. We also would like to catalyze a call to action to advance and incorporate health equity by design into health IT nationwide. And it is important to mention that the HITAC has already provided helpful recommendations to inform steps that we have taken to develop this concept paper, which includes recommendations around USCDI data elements, our algorithmic transparency work and more.

In order to move from concept to action, we need to co-develop materials with experts in this area such as yourself. And we are seeking public input and feedback on best practices, some of the work that you are doing in this area to build out a more robust set of guidance and recommendations around where we should be focusing, as well as what the broader ecosystem should be doing to implement the health equity by design approach. We look forward to your feedback today. If you could go to the next slide. I will turn it over to Medell to cover some questions that we have put together to help facilitate the conversation.

Medell Briggs-Malonson

Thank you so much, Tom. I also want to completely amplify what you said. I too am grateful. I know HITAC is grateful for the commitment and the prioritization of health equity by design by ONC and by, of course, our National Coordinator, Micky Tripathi and the rest of leadership, and thank you for all of your leadership in making this also come to fruition. This is an exciting time for all of us at HITAC because we are just going to open it up for discussion. ONC is asking us to truly address two primary questions right now, which I am going to go and take each one of them one at a time. We need your participation. We need some of your insights as well. One of the things that we are going to do is go through these two questions. But if there is any other elements that you think are necessary for ONC to consider as we are thinking about how we truly actionize and make sure that health equity by design is truly at the core fundamentals of health IT here in the country, this is our time to also share some of those insights.

The very first question is what actions should ONC consider to address health equity by design and also to address existing barriers? There are three bullet points to that. How should ONC approach health equity by design as it relates to standards, health IT certification, electronic health information exchange, coordination, and measurement and monitoring, as well as what aspects of health equity by design should





ONC prioritize for further HITAC consideration and deliberation? And then lastly, what additional policies or programs are needed to ensure commitment to and accountability for incorporating health equity principles and practices into health IT nationwide? We will first pause on this first question and make sure that everyone has a chance to read through the questions. And we will open it up for discussion. I was waiting for all of the hands to pop up. First, I see Fil's hand that was raised. We will turn it over to you.

Fillipe Southerland

Good afternoon, everyone. I wanted to comment on this first bullet point about access equity across really the spectrum of care settings coming from the long-term post-acute care sector. We have had difficulty even measuring uptake of health IT within the sector. Looking at whole person health and all of the clinical settings that are involved in whole person health behavioral community-based settings, etc., are really a key part to ensuring equity and allowing for important functionality like patient access to records and some of these more specialty sectors.

Medell Briggs-Malonson

Absolutely. Thank you so much. Katrina?

Katrina Miller Parrish

Thank you, again. And I am so glad, obviously, we are talking about this because it is so important to ensure that we have this structure to get the health equity component and framework in place in addition to all of the basic data process, health IT process, all of the things in the first bullet. The things that we are talking about here in HITAC and ONC and other places. Really, the design, I will say again and I know that many on this call will agree again, it really needs to entail the voice of the folks that we are talking about. People who will be experiencing the healthcare, people who will be using these kinds of either health information exchanges or patient portals or whatever the case may be really understanding from their perspective how this design should happen and what kinds of things need to be put in place so that they feel comfortable with how their data is being used, processed, presented, and provided to them to interact with.

I am not sure if Hannah is still on the call but I am just going to point a little over to Shift. I just saw her hand go up. I am sure that there will be interaction with her group Shift and this. And I will also mention the Institute for Medicaid Innovation has a lived experience group that I think could be very good in contributing some feedback to how the design happens and what goes into that design.

Medell Briggs-Malonson

Thank you so much, Katrina. To add a little bit more onto what you are referring to as well, the voice of the people should be incorporated from Day 1 all the way through. Historically, what we have done is tried to bring in the voice of the people after design, after an infrastructure is built. We need to make sure to center the voice of the people throughout the entire development of thinking about what this structure should look like across the board. I really do appreciate that. Michael?

Michael Chiang

Thank you for presenting this. I think this is great. And I guess my first comment is that I hope that these points make them into the first part of today's meeting, the strategic plan. I feel like, in a way, health equity by design should really be part of the overall strategic plan rather than a separate item.





In terms of the specifics, I have a few comments. One of them is that I think underserved areas and clinics may be a lot busier and may be technologically less advanced. We saw in the NIH AIM-AHEAD planning process that some of these practices did not even have EHR. That is just a plug for usability and efficiency in EHR design as one thing that would help underserved practices but really help everybody as a byproduct. Another point is that when I look at bias in the medical record, it seems to me that a lot of bias comes from subjective notes and “observations” that people write into the medical record. In other words, almost everything in the medical record comes from somebody making an observation and then entering it into medical record (e.g., even findings from history-taking and examination by clinicians are not truly objective).

I would really just make a plug for objective measures of data, which to me sort of often means laboratory tests, genetic data, and medical images. That is just a plug for interoperability of those types of data, and a note that image vendors outside radiology often do not adopt basic standards such as DICOM (I am most familiar with ophthalmology).

I guess the only other point that I would make is that coming from somebody who has a background in ophthalmology, I think it is going to be really important to emphasize usability by disabled people when it comes to apps and home healthcare. Vision, hearing, physical disabilities. Thanks for doing this.

Medell Briggs-Malonson

Thank you for all of those incredible comments. Bryant?

Bryant Thomas Karras

Thank you. Dr. Thomas, thank you so much for the presentation and I want to make two quick comments in answer to I believe the first question. I think that ONC can really point out or disclose to our federal partners the importance of continuous modernization. We made such an amazing effort after the stimulus bill and the HITAC Act that advanced healthcare, information systems, accessibility across all providers, not just the academic health institutions, but the Federally Qualified Health Centers (FHQCs) and rural critical access hospitals got that infusion in technology that elevated their ability to gather this data that we need for health equity. And we will hit the 10-year mark or more than 10 year mark now. That investment is aging and we are going to need a re-infusion to keep those lesser resourced, working just on the margins clinics and healthcare institutions as part of this solution. I am wondering what the continuous improvement, continuous maintenance strategy is to maintain health equity, as well as the health IT plan that we heard earlier today.

And the second comment is that I think public health has a true value in looking at not just the medical and health engagements of individuals but looking at the population and how the community's health really impacts the individual's health. I hope that that becomes part of this as well.

Medell Briggs-Malonson

Thank you so much. It absolutely needs to. Mark?

Mark Sendak

I have two comments. One directly builds off of Bryant but definitely these are comments I primarily wrote in the digital divide section of the discussion paper. The huge need for technical assistance for community and rural settings, as Bryant mentioned, ONC has played a big role in this before. Once again, I do not





know the formalities of requesting funding or requesting that certain types of programs be prioritized if and when funding becomes available. I would want to make sure that we are advocating for that type of, as Bryant said, maintenance of those programs and now we are talking about an entirely new class of technologies. Technical assistance is going to be increasingly important. I can tell you the problem that I see. The solution for me is quite a bit more complex. Folks here may have seen the announcement a few weeks ago about Epic releasing an AI assurance and trust suite of tools. From my perspective, this is the first health IT vendor that is directly getting into the tooling that every organization will need to monitor and evaluate AI products that are used in care delivery.

It is not surprising that this is coming from Epic initially, which already has a big footprint in AI and clinical decision support. The reality though is that most of the community and rural settings that we talk with, many FQHCs are not on Epic. And there will be a growing divide in terms of the tooling that individual settings have to actually look at safety, effectiveness, equitable implementation of technologies. Two options that I see, one is to try to promote the development of technical standards for health IT vendors to be able to have capabilities for evaluating and monitoring AI products. I am leaning more in that direction as a recommendation versus some type of reinvigoration of meaningful use that sets kind of goalposts that for certification, all health IT vendors need to be able to provide this type of tooling to support healthcare delivery organizations. Regardless of the solution, I just want to point out that that disparity is going to happen where certain types of products are going to further enable more rigorous use of these technologies whereas that is going to leave a lot of folks behind as well. We need to be proactive about that.

Medell Briggs-Malonson

Thank you for that and all of those considerations. I just want to flag that we have 20 minutes and we still have to get to Question No. 2. We are going to go Sarah, Hannah, myself, Anna, Ike, and then, we are going to move to Question 2 because we want to make sure that we have time for you to explain what your organizations are doing in terms of design and integration of health equity and justice principles. Sarah, we will go to you.

Sarah DeSilvey

Thank you so much. I want to briefly lean into the word accountability in that third bullet here. I know Medell probably knew that I was going to do that. I speak, of course, of my Gravity Project director of terminology hat. We are very involved in creating the data standards to address the social determinants of health. We are not contributing towards the collective goal of health equity until we use them to analyze outcomes and then, address structural solutions and policies to address what we find. I am very grateful for that accountability. And I just want to make sure that when we think about things from a HITAC perspective and an ONC perspective that we are really monitoring outcomes and ensuring that we are creating those structural solutions. I want to note that as part of our original USCDI submission from Gravity, outcomes was one of the data elements that we suggested. But it was a little bit premature at this time. There is a lot of conversation in the ecosystem on what it means to be accountable to the employment of terminologies to address social determinants of health.

I want to elevate how it is connected to other entities within HHS like the CMS health equity framework, which directly holds us accountable to the data that we are collecting. Thank you, ONC, for putting accountability front and forward and I definitely feel like that is something that should be centered in any





data health equity by design initiative is ensuring that we are accountable to the data that we are collecting and aiming them toward structural solutions. Thank you so much.

Medell Briggs-Malonson

I cannot agree with you more. If we do not have accountability, we will not achieve health equity and justice. That accountability pieces so critical. Hannah?

Hannah Galvin

I want to commend this work. I have three quick points. First, around digital divide and echoing many of Mark's points, to highlight what we had talked about previously with the federal health IT strategic plan that really infrastructure is key here around the digital divide as well as digital literacy and thinking about that. I also think as part of the digital divide is brought up but including voices from historically marginalized populations when looking at overall strategy at the federal level on down is really key. And when you think about interoperability, voices from communities where interoperability has not always been a good thing where there is higher levels of medical mistrust having those voices at the table and understanding those perspectives is really important. I think that needs to be considered in health equity by design. Finally, my last point is just to caution us around too many data elements. One of the easiest ways to address health equity and one of the ways that we have been doing it now for the past number of years is let us just gather more data.

Let us just ask for more data elements. There is some potential for inequity in that as well in that organizations or community health centers that are staffed in a very lean manner spend more of their time trying to collect all of these data elements and spend less time on providing quality care to their populations. We should also really think about harmonization of these data elements. The United States Office of Management and Budget (OMB) has just released their new race and ethnicity standards. Many states have not aligned there so there is confusion. We have talked about data quality. Collecting data to help support further efforts is great. We need to think about what is realistic and how can we do this in a way that is feasible and strategic.

Medell Briggs-Malonson

Hannah, thank you. What you said is incredibly correct. Some of our lower resource environments and organizations are sometimes often overwhelmed. If we are just collecting data without applying it to ensure that we are achieving greater health outcomes, it is purposeless. I am going to share some thoughts on Question No. 1 in terms of what actions should ONC consider. I have been in the space in terms of addressing health inequities for, I will not date myself, but I will say for over 20 years. I have used technology in order to try to ensure that we are doing what the whole purpose of our work is and that is to improve the overall health and well-being of individuals and communities. When it comes to the thoughts of health equity and justice, I like to say it is a beautiful marriage between public health, population health, quality improvement, as well as social justice. And you have to get down to the root of those social injustices that are causing the health inequities to begin with.

When you think about that beautiful marriage between all of those different sectors, it is very challenging for a lot of organizations to wrap their minds around how do we even do this because it is not just the data. It is not just looking at the data. It is a whole entire framework of how you think about what are we trying to achieve in our goals. Then, using the data, using the interoperability to identify where the inequities are.





Then, you develop the interventions with community, with those populations and you have to monitor those interventions to ensure that you are getting to the health outcomes that you need. There is a true structure of how we incorporate health equity by design into our technologies in order to help to elevate and leverage what we are trying to achieve.

One of the things that I think ONC can absolutely do is to help to develop a beginning framework, a beginning toolkit, so that the vast majority of health systems, whether they are rural or located in more urban areas or whether they are community-based organizations, whether they are academic medical centers, they can step through these processes in a thoughtful way and apply it to their populations so that they truly can come along with us on this journey. That is the No. 1 question that I get every time I present not only in this country but globally is how do you do this work? Where should we start? What is the very first thing that we have? And there are true priorities that all institutions have to have in order to try to address this. That is what I would say would be an incredible first step, is actually pulling together a recommended toolkit framework that just gives the basics of what is needed to start this journey and that would need to be developed by a multidisciplinary group, probably HITAC as well as many other experts, as well as our community in order to address and push that work forward.

Those are just some of my thoughts from the very beginning. Anna, we will turn it over to you.

Anna McCollister

Compared to your thoughts, Medell, I feel like my thoughts are somewhat anemic.

Medell Briggs-Malonson

Never that, Anna.

Anna McCollister

I have two major points. One is it is great to say that everybody needs to be included and everybody needs to be at the table. There needs to be budget applied to that and training. You cannot just throw people into an environment, especially patients or consumers, whatever word that you want to use, and expect them to be able to provide meaningful content and expect them to be able to assertively engage amongst a room of people with fancy credentials and titles. That is rarely considered. We have won a lot of battles over the years to getting a voice at the table. Finding people who have the time, the resources, to be able to do that is somewhat challenging. Getting people, whether it is of color or different backgrounds is incredibly difficult because I do this as a volunteer. This is all volunteer work for the federal government. Nobody is paying me to do anything. I do not have a salary that covers my time. That is not something that many people can do.

In addition to that, one of the thoughts that I have is that I feel like there are a lot of things that, not just ONC but more broadly speaking, people will put out as rules or guides or whatever. But there is no enforcement or no auditing to see if different organizations are actually meeting those goals or objectives and whether that is enforcement or perhaps ONC can use the certification process to require friction audits to whether or not people can actually do the things. Whether it is something as simple as a portal, can people access the portal in a timely fashion? Is it usable? Can people access consistently their data through a EHR or whatever system may be needed? It is one thing to say that it is required and to have a certification process that technically on paper meets certain standards. But in terms of what the applications are in the real world





and whether or not that actually happens in the real world, I feel like there should be some kind of an auditing process within the context of certification that should be monitored moving forward.

Medell Briggs-Malonson

Thank you for those important concepts and definitely that auditing and that accountability and also, supporting the time of people. We definitely know that is needed. Thank you. We will go to Ike and then we are going to move to Question No. 2.

Steven Eichner

One of the promises we have called out with health IT for a long time is patients not having to re-tell their stories and the ability to share information between providers to really make life easier and better for patients. Thinking about health equity and AI going forward, I think one of the things we need to consider is how do we ensure that patients, particularly those with rare conditions that are not easily identified, do not have an extra burden to have to re-tell their story to look at exceptions to what might be a computerized decision support that is being recommended on a more limited set of information and looking at having to explain why they are an exception to what might be a more general recommendation from a standards perspective.

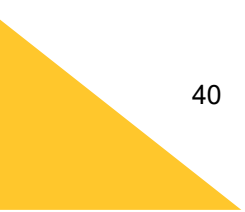
I think we need to think about how to incorporate into IT standards from a behavior standpoint that the technology needs to evaluate a wide range of conditions and account for a broad number of exceptions whether they be race, ethnicity, or other medical conditions straight out so that patients do not have to tell their stories again and again and again and avoid delays in care because they have to go through an exceptions process to avoid something that might be recommended by technology that might work very well for 99.7% of the population. But if you are the 0.3%, you are then stuck with an additional burden of time and energy to explain what is going on. I think that is something that we need to look at.

Medell Briggs-Malonson

I agree. We have had these conversations about the importance of focusing on those with rare conditions and also those that are made in terms of numbers, in general, maybe much less than if the greater population and ensuring that we are supporting them in all of the ways possible. Thank you for that comment. We have about eight minutes left so we are going to go into our rapid round for No. 2. How do your organizations design and integrate health equity into your health IT infrastructures and practices, including examples related to health information, collection exchange and use? And for those organizations that do not directly deliver care, how do your organizations account for health equity? Bryant, your hand is up next and I will put my hand up after you.

Bryant Thomas Karras

I put some links in the chat. Our agency has made health equity a huge priority. Dr. Umair Shah I am sure many of you have heard speak on this topic and perhaps saw his comments in the PBS special The Invisible Shield. As a homework assignment, I think everyone should watch The Invisible Shield that talks about how we can deliver health and do so in an equitable fashion across our whole population. We take very serious our responsibility to share that information, make it useful for decision makers. I included links to health disparity maps, as well as our strategy for health equity, which includes some model legislation that other states can use and follow. And it includes, as a starting point requirements that to practice medicine in the state of Washington, continuing education credits need to include a minimum of two hours in health equity





training. And it is putting practice where our mouth is and making sure that we do not just talk about it, we make people do it. Thank you.

Medell Briggs-Malonson

Thank you, Bryant. I agree with everything you said. And very quickly, I am happy to expand on this after this meeting. We at UCLA are also committed to health equity and justice, which is fully integrated into all of our various different operations and practices. How we do that is we have multiple governing boards that actually not only look at the overall care but also specifically other councils that are looking at the equity that we are preventing throughout our organization.

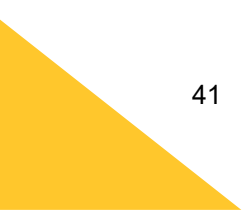
In terms of incorporating equity and justice into our health IT systems, there is specifically what we like to call health equity innovation insight and informatics governance committee that I chair, which is comprised of health IT leadership, population health leadership, as well as nursing leadership, physician leadership, health equity leadership, and others and which we have actually developed a whole framework of how to design our EHR and all other technologies within our system to do what I like to call the pyramid where we have the basics, which means all of the various different demographic characteristics that any of our conditions health system wide can be disaggregated by. And we are actually ahead of what OMB is recommending right now. We have incorporated so many of those elements into our system. The second tier is also making sure that we are bringing in all of the social drivers of health data and, most importantly, the referrals out to all of our community-based organizations.

The third tier that we do is actually look at what we like to call some of our key elements, our key offerings, especially as an academic medical center. And then, we have several other tiers. We take all of this data to truly survey all of the care that we are providing in terms of access, process, outcomes, and experience so that we can identify where any of those health inequities lie. Once we see where those health inequities are, we go deeper into it through intersectionality in order to see really where the target population is. From there, we develop interventions, not only internally with the organization but also with our community partners. We monitor our progress there. It is really based off of Lean Six Sigma frameworks that we do here at UCLA Health while also bringing community and focusing on justice principles. I just wanted to share some of the things that we do there. Hung, you are up next.

Hung Luu

Thank you. I am at a pediatric healthcare institution in North Texas. And our institution was one of the first and had one of the longest running transgender care clinics in the deep south. We made a concerted effort to implement EHR functionality in order to display the preferred name in order that first line employees such as phlebotomists and access folks could use the appropriate names so that the patients could feel comfortable and safe in receiving care. We made use of the existing functionality that included collecting information, not just on legal sex but also preferred sex and then, leveraged algorithms to ensure that if there was a discrepancy between the two that we had a way to display the appropriate reference range because very likely, most of the time these patients were undergoing gender affirming treatment. The reference ranges could change depending on what type of treatment they were receiving. We worked closely with the clinic to be able to make sure that what we were displaying was appropriate for the patient. Things have changed but the commitment to health equity remains the same.

Medell Briggs-Malonson





Thank you, Hung. That is such an important piece that you brought up about those things that are in our EHR in terms of sex assigned at birth, legal sex, as well as gender identity and how that truly does directly impact patients, especially patients that are receiving gender affirming care. Thank you so much for that example. Michael? You will be the last one and then, we are going to transition to public comment.

Michael Chiang

Thanks. I will be brief. I just wanted to call out from NIH one example of a Common Fund project in a primary care research network. I think it is really based on a lot of health equity principles that just got announced recently. There is a broader issue, which is that it is acknowledged in the strategic plan that we are gradually transferring care from the super-duper subspecialized office to the primary care office like maybe eventually to the patient's home. I really hope this can be a way to democratize medical care in the future.

Just to call out: maybe we need to be doing some work now to identify data flows and new models for healthcare that can be based on that sort of shift. I hope that would benefit people in Tom's clinic on the south side of Chicago. Perhaps there will also be people who work on Michigan Avenue who would love not to wait for three hours in the doctor's office. I just love that you are doing this.

Medell Briggs-Malonson

We are all very appreciative. Thank you so much for presenting this to us. We would love for maybe even HITAC to have a task force because you can see all the motivation and the passion behind HITAC for this topic. We would love to present that as a question and an official recommendation to ONC leadership to consider that. I will transition back to Seth so we can transition into public comment.

Public Comment (02:40:21)

Seth Pazinski

Thank you, everyone, for the robust discussion through the meeting. I appreciate everyone's participation throughout. We are going to move into our public comment process. If you are on Zoom and would like to make a comment, please use the raise hand function, which is located on the Zoom toolbar at the bottom of your screen. If you are participating by phone only today you can press star nine you raise your hand. Once called upon, press star six to unmute and mute your line. We will give folks a minute to queue up. While we wait, I will make two quick administrative updates. One is just to remind everyone that the next HITAC meeting will be held on June 13. We are looking forward to that. And I will also remind everyone that all of the materials from the meeting today as well as all HITAC materials can be found on HealthIT.gov.

It looks like we have no one on the phone. Let me just check that we do not have any hands raised. There are no public comments at this time so I will turn it back to Medell and Sarah for their closing remarks.

Sarah DeSilvey

I just want to recognize that we did have the public comment in the prior session. Do you want to raise that question now in the maternal health USCDI? We had a public comment question in the chat. I am trying to give space for that person if they want to elevate it.

Seth Pazinski

Yes. We welcome the opportunity to do so. I can voice that if I can find that in the chat.



**Sarah DeSilvey**

It was regarding validation of the USCDI+ maternal health elements. And it came from a member of the chat with the first name of Beluh. I want to make sure that we do not miss that. If they feel comfortable, then that is fine. I just wanted to circle back around. Thank you so much.

Seth Pazinski

Thank you. I will transition then back to Medell and Sarah to close this out.

Final Remarks and Adjourn (02:42:40)**Medell Briggs-Malonson**

Thank you to all of our presenters today. It is very clear that we are on a very positive journey ahead of us. We are very grateful for all the information that you shared with us and for allowing us to provide our insights. And thank you so much to the HITAC. This was a fantastic meeting. We really appreciate all of your comments as well as perspectives. And I am sure that we are going to continue to share even more. I will turn it over to my amazing co-chair to close us out.

Sarah DeSilvey

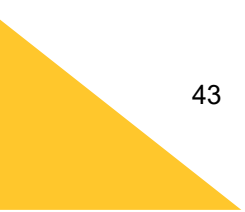
As usual, Medell covered it. I did not have much more to say. Thank you so much for your time and we do value all of your time so much. HITAC members and ONC, thank you for giving us the space to add our expertise to these very critical topics that are very near and dear to the heart of the co-chairs. We hope you have a lovely rest of your day and we will see you at the next meeting.

QUESTIONS AND COMMENTS RECEIVED VIA ZOOM WEBINAR CHAT

Medell K. Briggs-Malonson: Congratulations, ONC!!!!

Katrina Miller Parrish, MD: 100%!!

Deven McGraw: ONC - an example of government at its best





Keith E. Campbell: It would be great if maybe goals 4, possibly 2, could specifically call out data quality.

Steven Eichner: +1 Hans

Rochelle Prosser: +1 Hans and Keith

Rochelle Prosser: +1 Dan on privacy and data encryption

Seth Pazinski: Appreciate the data quality feedback. ONC has focused on data quality in recent LEAP work. For example, <https://www.hhs.gov/about/news/2024/05/13/hhs-announces-leap-health-special-emphasis-notice-ai-behavioral-health-focused-projects-fiscal-year-2024.html>

Keith E. Campbell: +10 to Michael for focus on quality...

Anna McCollister: Completely agree on issues related to data quality! Especially as we move into incorporating EHR data into AI, if the data quality isn't solid, it introduces potentially significant problems and dangers, especially if the algorithms are not transparent.

Bryant Thomas Karras: +1 to Hans, I fear there is already a fiscal cliff 2026 for the needed sustainability plan for PH data Modernization (that should be labeled Continuous Modernization)

Steven Eichner: Quality data, including completeness and accuracy, are also needed by public health.

Sarah DeSilvey: Michael, thank you for this. Your comment calls to mind some of the thoughts on our Health Equity in AI Panel last month. Specifically reflecting on the hidden labor of AI highlighted by Dr Rae Walker. Important topics.

Steven Eichner: Transparency regarding data sharing and utilization is important. How can individuals best be empowered to manage who has access to their data, especially for individuals where it is difficult to anonymize the individual?

Katrina Miller Parrish, MD: Great point Keith - data quality needs to be reviewed and managed, not assumed!

Naresh Sundar Rajan: I fully support Keith's point. Quality which often perceived as an intrinsic factor in health interoperability needs to be a standardized and I fully support this view. This increases trustability, transparency, equity, reproducibility and etc. not only from an AI algorithm perspective, but to the point of even clinical decision making in interoperable systems.

Sarah DeSilvey: @Michael, If we are to be accountable to the expertise we gathered on this topic, Yes!

Kikelomo Oshunkentan: @Mark -100%!

Hans Buitendijk: Adding to Mark that this concept can be expanded to generally considering how to enable federated research thus enabling wider participation and reduced, unnecessary movement of health data.

Sarah DeSilvey: 100% Medell, this is also a topic our amazing Health Equity in AI Panel experts reiterated!





Sarah DeSilvey: Hannah, echoing this need from VERY rural primary care

Hannah K. Galvin: Agree with digital literacy, Medell - and in all languages!

Sarah DeSilvey: Of note, Gravity addressed both digital literacy and digital access in 2023 and has a host of current and incoming resources and standards to assess and address these topics.

Sarah DeSilvey: <https://confluence.hl7.org/display/GRAV/Digital+Literacy>

Deven McGraw: The legal definition of de-identification in HIPAA - which is one that is widely recognized, even by entities not covered by HIPAA - has never been a zero risk of re-identification standard.

Eliel Oliveira: Given all the points on data quality which I am also in agreement, I wonder if ONC should be charged with the authority to define and regulate data quality certification for certain systems. Data quality as many of you know includes several aspects and some such as completeness and conformance at least could be under ONC certification requirements. Other aspects of quality characterization could be done by other entities with ONC's oversight.

Sarah DeSilvey: <https://confluence.hl7.org/display/GRAV/Digital+Access>

Katrina Miller Parrish, MD: EMR training/ retraining should be part of Maintenance of Certification, just like clinical knowledge.

Bryant Thomas Karras: @deven We have repeatedly made note of limitations in de-identification... there needs to be small numbers policy to protect communities who can be identified easily by an inclusion of even their race when they live in a rural zip code where they may be the only one

Mark Sendak: Agree 100% Anna

Steven Eichner: @Bryant @deven- And some method for consistently recognizing the existence of the conditions these individuals have.

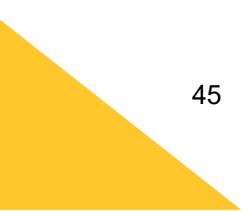
Sarah DeSilvey: Thank you all for this excellent conversation and thank you, ONC for this robust plan and your willingness to engage with us on this topic

Katrina Miller Parrish, MD: Great work, thanks for managing feedback!

Dustin Charles: Thank you all for your feedback! Please submit more through the public comment process at healthit.gov/feedback

Steven Eichner: +1 Michael

Deven McGraw: @Bryant Thomas - totally agree. Safe harbor methodology, used by many, takes no account of context or small numbers. Expert methodology requires consideration of those factors - yet people are often reluctant to use it because they don't have the statistical expertise on staff or the funds to pay for it. And agree with you as well, @Michael. We provide no transparency, much less patient consent (opt-in or opt-out rights) when data are "de-identified".





Bryant Thomas Karras: @Michael for some de-identified data sets collected by Public Health and then shared with CDC, consent is not required. so I agree with the premise but there may just need to be informed education (not necessarily consent)

Liz Turi: @Hannah - USCDI+ is intended to be extensional - as by default, USCDI is always included. That being said, some domains may want to represent USCDI elements within their domains, particularly when highlighting specific valuesets that may be important to included as domains/use cases thing towards implementation.

Hannah K. Galvin: Thanks @Liz. In reviewing USCDI+ BH, many core elements were included but not all; we left this as comments on USCDI+BH as this was a little confusing.

Kikelomo Oshunkentan: @Katrina - 100%

Medell K. Briggs-Malonson: Agree completely, Katrina.

Michael Chiang: Just for the record in response to @Deven and @Bryant: I think there are many broader societal areas where these privacy & consent come up (e.g., we all have "PII" owned & presumably used for profit by social media, online stores, supermarkets ... generally without informed consent & perhaps without informed education). I do think it's great that we are having these conversations in the healthcare & research fields about how to most appropriately deal with these issues.

Liz Turi: We are expecting to have the USCDI+ MH data set published by early June.

Kikelomo Oshunkentan: true

Katrina Miller Parrish, MD: I agree Dayo, I think we need protocols for specific patient complaints nowadays with required levels of response and escalation. Then perhaps USCDI+ can ensure the data capture and quality oversight can be done.

Hans Buitendijk: What are the implementation plans for USCDI+ Maternal Health once published?

Shelly Spiro: Pharmacists especially in the rural setting has a resource for pharmacists through National Alliance of State Pharmacy Associations (NASPA) Maternal Health Service Set for Pharmacists <https://naspaspa.us/blog/resource/maternal-health-service-set-for-pharmacists/>

Sarah DeSilvey: We have until noon for this topic

Beluh Mabasa Ginting: Who is responsible to validate all the data? Thanks

Sarah DeSilvey: Beluh, thank you for your question. We will capture this for the public comment period

Katrina Miller Parrish, MD: Thank You!!

Christopher Muir: @Hans - In addition to the IGs we are also publishing information resources for software publishers to give them some additional resources for implementation. And, we are also planning pilots of the data sets.





Christopher Muir: @Hans - I was speaking specifically about Maternal Health

Sarah DeSilvey: See you all at ~ 12:10.

Sarah DeSilvey: Thank you, Christopher!

Seth Pazinski: ONC Health Equity by Design Concept Paper -- <https://www.healthit.gov/topic/health-equity>

Seth Pazinski: Public can provide feedback on the paper through Monday, June 10.

Hannah K. Galvin: Thanks, Katrina - yes, we at Shift read through Concept Paper and commend this work. Agree with Medell that individuals and patient voices should be incorporated.

Shila Blend: Ditto Mark's comment. That's what I was going to bring up. Our rural communities need assistance and support and often they are understaffed and wear multiple hats

Rochelle Prosser: Inclusion from all entrance points in the healthcare ecosystem is necessary. Of course at this point in our progress many community and healthcare centers have shuttered so are there elements to address the maintain and scalability for these communities left behind is Public health? Most public Health agencies without healthcare hospitals or centers are left out of the funding ecosystem.

Hannah K. Galvin: Absolutely agree, Anna. Per the PCORI framework and from an equity perspective, it is important to provide stipends and training is incredibly important as well.

Dustin Charles: Regarding Health Equity by Design and the Strategic Plan: when drafting the Plan, we did place emphasis on equitable design, implementation, and use of health IT and connected health equity throughout the Plan's objectives

Bryant Thomas Karras:

to discussion question #2:

<https://doh.wa.gov/community-and-environment/health-equity>

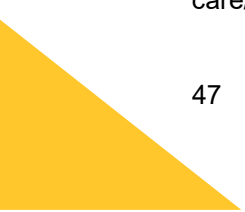
<https://doh.wa.gov/data-and-statistical-reports/washington-tracking-network-wtn/washington-environmental-health-disparities-map>

<https://doh.wa.gov/public-health-provider-resources/healthcare-professions-and-facilities/health-equity-continuing-education>

WAC 246-12-820 requires that health care professionals in WA must complete a minimum of two hours in health equity continuing education training at least once every 4 yrs

Keith E. Campbell: Already watched, and have recommended that others watch "The Invisible Shield"... A really good program.

Michael Chiang: One NIH example regarding #2: <https://commonfund.nih.gov/clinical-research-primary-care/Primary-care-research-network-Research-Opportunity-Announcement-FY24>





Sarah DeSilvey: happy to hear so many accountability examples!

Hannah K. Galvin: CHA has a Health Equity Steering Committee, which has included a task force to standardize filters on race, ethnicity, language, SOGI and other demographic information across all data.

Sarah DeSilvey: Thank you, ONC for this critical work.

QUESTIONS AND COMMENTS RECEIVED VIA EMAIL

No comments were received via email.

RESOURCES

[HITAC Webpage](#)

[HITAC - May 16, 2024, Meeting Webpage](#)

