Health Information Technology Advisory Committee℠

The Office of the National Coordinator for Health Information Technology

Transcript

HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC) U.S. CORE DATA FOR INTEROPERABILITY TASK FORCE 2021 MEETING

September 21, 2021, 3:00 p.m. – 3:30 p.m. ET

VIRTUAL

Speakers

Name	Organization	Role
Steven Lane	**Sutter Health**	**Co-Chair**
Ricky Bloomfield	Apple	Member
Hans Buitendijk	Cerner	Member
Grace Cordovano	Enlightening Results	Member
Jim Jirjis	HCA Healthcare	Member
Ken Kawamoto	University of Utah Health	Member
John Kilbourne	Department of Veterans Health Affairs	Member
Leslie Lenert	Medical University of South Carolina	Member
Clement McDonald	National Library of Medicine	Member
Aaron Miri	The University of Texas at Austin, Dell Medical School and UT Health Austin	Member
Brett Oliver	Baptist Health	Member
Mark Savage	Savage Consulting	Member
Michelle Schreiber	Centers for Medicare and Medicaid Services	Member
Abby Sears	OCHIN	Member
Sasha TerMaat	Epic	Member
Andrew Truscott	Accenture	Member
Sheryl Turney	Anthem, Inc.	Member
Daniel Vreeman	RTI International	Member
Denise Webb	Indiana Hemophilia and Thrombosis Center	Member
Michael Berry	Office of the National Coordinator for Health Information Technology	Designated Federal Officer
Michelle Murray	Office of the National Coordinator for Health Information Technology	Acting Designated Federal Officer
Al Taylor	Office of the National Coordinator for Health Information Technology	ONC Staff Lead

HITAC Meeting Debrief and Review of HITAC Amendments to Task Force Recommendations/New HITAC Recommendation (00:00:00)

Steven Lane

Terry O'Malley, who did suggest the addition of transitions of care as a priority related to shared care planning and list of high priority use cases. This was discussed by the HITAC and added as an amendment to our recommendations and subsequently approved. I do not know if anybody had any questions or comments about that in particular. Hearing none, let us go on to the next slide. In our Recommendation 3 was a lively discussion, which lead to a couple of changes that were made before the recommendations were finally approved. Again, for those of you who missed it, just to give a little flavor of this. We actually went through and loaded on the recommendations with just Terry's amendment on the transitions of care. When it came time to the vote, there were actually two main votes on the entire package of recommendations. Carolyn Peterson and Alexa Snyder who are serving as patient and family advocates with a key focus on disability did not feel comfortable with the wording that we had initially. As we went through the recommendations initially, there was a discussion of that.

An acknowledgement that there was an opportunity to think more deeply about this, but it did not come forward as a specific amendment the first time around. So, they voted May on the package as a whole and then we actually went back in the 11th hour and re-discussed this. Asked for specific amendments and included those. So, this with the red text was the final wording that was voted on by the HITAC and has subsequently been transmitted to the national coordinator. That transmittal is still in review, so it has not been posted publicly. But suffice it to say that there was a lively discussion about functional status and disability and the terminology that is being used. I think an honest acknowledgement that there are opportunities to improve the way that ONC and the OIT community as a whole manages information about function and abilities. So, this was the change that was made in our recommendations before it was voted on by the HITAC and approved. Before I open this up for discussion, I just want to give the full flavor.

So, on the next slide, this conversation also led to an additional recommendation that was added to our recommendations. So, we had nine recommendations and the HITAC added on an additional 10th recommendation before transmitting our work to the national coordinator. This is numbered as a task force recommendation, even though it was not one we made as a task force. It was included in the recommendations that came out of the task force. I think that is a subtle difference, but I wanted to make that clear to all our task force members. But the recommendation that HITAC added before putting in our body of work to the national coordinator, was that ONC should charge the HITAC to convene this task force to discuss the HITAC's recommendation that ONC supports a social model of disability. Including the advancement of relevant data elements.

So, that is a mouthful. There is a lot there. As I say, it is a lively discussion. I have had a follow along discussion with a number of you about this. I think Mike, perhaps you can just say how this came down with regard to the HITAC ONC, because I do not believe that our task force is actually going to be charged with this, even though that was the HITAC recommendation. So, Mike, maybe you can clarify that before we open that up for discussion.

Mike Berry

Yeah. Sure, Steven. This, along with every other HITAC recommendation is captured by ONC and is discussed internally and we will decide what to do with this particular recommendation, as well as the

others. Should the USCDI task force look at this recommendation or should an upcoming different task force look at this recommendation, or should it be both? This is something that we have to discuss internally and then tell HITAC appropriately at a later date.

Steven Lane

Thank you for that, Mike. So now if you can back up a slide to the on with the edits. So, I did want to invite Mark to talk briefly, Mark Savage. Mark's done a lot of work in this space, and this definitely overlaps with the work of the gravity project. I know Mark consulted with a few people and did you want to share something about these data elements, and specifically, where they are in the evolutionary process Mark?

Mark Savage

Happy to do so. Thanks so much, Steven. So, the recommendation includes a list that the gravity project had offered to the task force. We had listed in our recommendation to the task force, functional status and cognitive status separately thinking that collectively, they represented two significant components of what has been called, disability status. But they are often tracked separately. The census does that, reports separate statistics on functional status and cognitive status. It also, that nomenclature and separation also lines up with evolving use of the term, disable disability, in the community. I am not a deep expert in the community, but I have worked with a lot of folks. I was not able to participate in real time on the HITAC call, but I did listen to it afterwards and I went back and talked to some folks because I had thought there was some disfavor with the use of the word, disability. So, I am happy to share the results. I talked with an expert at the American Association of health and disability and one at Disability Rights and Educational Defense Fund. Both nationwide organizations. Both acknowledged that the word disability is used frequently.

But when you get down to the assessments, as one of the people mentioned. The assessments do not ask, or tend not to ask, do you have a disability. And the reason they do not is because many individuals do not self-identify as disabled. Or they do not want to answer yes to the label, disability. So, asking the question that way underestimates where people are. So, I looked at some of the assessments that CMS uses for example and nowhere found the word disability or disabled in them. They are taking a different approach and that lines up with what people are telling me. It is not a wholesale evolution in the language but tending to move forward with words like functional status and cognitive status. Second point was, I asked does disability status really just overlap with cognitive status and functional status? The answer was for the most part yes, but there are some things that probably are not included in functional status and cognitive status. So, something to keep in mind if we are trying to be comprehensive. The three examples that this expert noted were mental health issues, autism and speech or communication impairments.

I have not delved into that myself, but I just flagged that it may not be a perfect overlap even if it is a pretty significant overlap, perhaps for USCDI purposes. The third point is just my own, it is not one that I vetted with either of these experts. But it goes to the other slide, Steven, about the social model. I did take a look at that, too. This is perhaps overgeneralizing a bit. But the difference is between the medical model and the social model. The medical model tends to say the issue is with the individual. The individual has a disability. The social model tends to say that issue is with the environment. The environment has not adjusted to the differing abilities. My observation is that is actually true of a lot of things. I mean, the reason that it is so good that we have got social determinants of health data elements in USCDI now is because there are environmental and social factors that explain a lot about health status.

So as a recommendation, I would say that this seems to be about far more than disability or functional status or cognitive status. I think it is probably a perspective, a way of looking at things that goes across the board. Anyway, that is the result of my phone calls to people to try to get some thoughts from experts about the conversation.

Steven Lane
Thank you so much, Mark. Dan, you your hand up.

Daniel Vreeman
Yeah, thanks. I have a lot potentially to say about this but will hold this for our whatever reconvened group that might pick this up. Having been deeply involved in this world for essentially my whole career, the two things I had mentioned are the current proposal that is in USCDI is based on the WHO's framework for functioning, which is called the international classification for functioning, which explicitly is the newest iteration. i.e., a bio psychosocial model that is intentionally trying to unify the prior distinctions between the medical model and the social model which is first kind of positive by Nagi back in the '60s which was very useful. But the ICF is for sure the preeminent way of organizing these constructs. So, in fact to some extent what is on the table for ONC to consider has already taken that into account. I do not think the HITAC numbers may be appreciated that.

But along with that framework comes very helpful constructs for describing the functioning and its applicability across body functions, structures, activities and participation which actually unify this perspective of things related to the physiology, things related to individual characteristics, the environment and social factors as well. But to Mark's point, the other I think useful component of the ICF is the framework for understanding both those body functions and structures, as well as the activities so that we can think about things like mental functioning as well as the physical functioning. Again, when I say functional status or functioning, I am thinking not just physically, right? But the physical components of that combined with a mental component of it and express themselves in the individual's ability to carry out IDL, instrumental activities of daily living. I think these are fantastic. I am so excited and glad that this good so much attention at HITAC. It is worthy of it. As the gravity project illustrated, it fits the criteria for our multi-modal multi-use case information. But definitely there is a lot to dig into.

So, in some sense I would fully support the spirit of what they were trying to convey in this recommendation, but actually in some ways the specific language of, quote, a social model of disability, is actually somewhat outdated. We now have a better internationally developed over 20 years framework that includes the universe of the medical and social combined. Thanks.

Steven Lane
Thank you so much. Again, would what did you say the ICDF stands for?

Daniel Vreeman
The international classification of functional disability and health. It is an official member of the WHO's classification family. Akin to ICD. In fact, ICD11 contain components of the ICF inside of it and it specifically has links to enable kind of the joint used together.

Steven Lane
Marvelous. Thank you. Clem, your hand is up?

Clement McDonald

Yeah. I wanted to comment maybe some of the **[inaudible] [00:15:02]** I wish instead of fighting with words we actually got into the meat. There was a panel and a couple of people came up with the idea that they really are problems with getting measures of functional status in routine care. And I think what really needs to do is to focus down on which one should we be using and get people to use them. Medicare actually does a good job with some of their other forms. So that is one side of it. The other thing is you got to be conscious of turning the eight minutes or 10 minutes providers have with patients into a 40-minute data collection effort. So, there is tension between the two.

Finally, one last thing, I wished we could have gotten in two more things into the request for three because NIH has asked for it and NIAA had asked for these things about a year and 18 months ago and that is a questions about drug abuse and questions about alcohol use and they are simple. The audit C is the one they were asking about. These are standard ones. I wish we could find a pathway to get these questions also in in some other dimension of some social functioning. With drug abuse, it is so important with the death rate is twice the death rate from car accidents now. Anyway, that is my pitch.

Steven Lane

Thank you, Clem. Great input. And I think it really does highlight the opportunity that ONC has and was transmitted by the HITAC to really dig into this. As I thought about this since the meeting, both a clinician and informaticists I can see the value of having functional status information, cognitive status information standardized and transmitted along with the USCDI. I do hope that ONC takes this on and figures out where this will be looked at. The USCDI component of this is a sunset. There is more here than, what are the data elements and classes that will be included in the USCDI. So, in a sense, I think it is a good decision to not immediately send this back to our task force, but to do some additional work and determine if or when it is appropriate to come back to us. But perhaps next year we will have a chance to do that.

Clement McDonald

So just one thing. I think they suggested that the activities of daily living might be the best and someday, Mark, I would like to get your feedback on some of those.

Mark Savage

Happy to do that.

Steven Lane

So again, we are at time for public comment so we will transition over to that. We may have a few minutes at the end to wrap up this discussion. But let us go to public comment

Public Comment (00:18:11)

Mike Berry

All right, thank you, Steven. Operator, will you open the line for public comment.

Operator

Thank you. If you would like to make a public comment, press star one on your telephone keypad. A conversation tone will indicate your line is in the queue. You may press star 2 if you would like to remove

your line from the queue. For participants using speaker equipment, it may be necessary to pick up the hand set before pressing the star key. One moment while we poll for comments.

Mike Berry
While we are waiting, I want to thank all of the task force members and in particular, especially Steven and many of you for many long hours of hard work over these past many months and for our program lead for Dr. Al Taylor for their great work and on behalf on those of us at ONC, we really thank you for your time and effort. I think we kicked off in February and here it is in September, and we are wrapping up for this cycle and just want to thank you. We really appreciate it. Operator, do we have any public comments?

Operator
There are no comes at this time.

Mike Berry
All right, thank you. Steven?

Steven Lane
Yes. So I want to echo your thanks, Mike. To you personally and to Al and the entire team, the Accel team and other folks who supported the work of this task force. I think we did a pretty dang good job. I think we did our homework and turned in a good set of recommendations and I think we saw earlier in the year that they actually did move the needle on USCDI Version 2, and I anticipate they will also help to end the crafting of the draft. I want to thank all of the task force members for your time and participation which has just been incredible including those who needed to step off the boat part way down the river. It has been a great group and I do hope that a number of us have a chance to come back together next year and continue this work. With that, I would like to invite Al to say a few words. Al, you have missed a couple of meetings, but your guidance and participation has just been incredibly valuable and important to the work of this task force. I would love to hear any thoughts you had about the presentation we made to HITAC or anything else before we wind down.

Al Taylor
Thanks, Steven. Appreciate the kind words and I also want to re-iterate the appreciation for all of the hard work. Steven, Leslie, especially the many hours outside of the task force meetings as well on working to turn this into a much better product. I do not have any specific words of advice or anything. I think the recommendations really are very useful, actionable. That was my goal, to make sure that if I felt like I was pushing a little bit in the particular direction, it was primarily just to get the recommendations and the very succinct actionable ones that ONC could actually take and sink their teeth into. I want to thank everybody for that and for not getting too upset by some of my use of force and I look forward to working with as many as possible in the future. Future iterations of this task force or possibly other HITAC activity as well.

Mike Berry
Thank you, Al. Anyone else on the task force have anything to share in our last 90 seconds here? Sasha, I see you made it. Go ahead.

Clement McDonald
Thanks, Steve. He worked so hard for so long. As leader of this committee and I think he has kept us in line and gotten stuff done. Both of them really are laudable. Thank you, Steve.

Mike Berry

Well, it has truly been a pleasure to work with all of you and ONC. This is one of the most fun committees that I am on, and I am on a bunch of them. Again, I hope we can meet again early next year and continue this important work. With that, we are at time on this very, very quick meeting today and just thank you all again and have a wonderful day.

Steven Lane

Thanks so much.

Adjourn (00:22:48)