

**HIT Standards Committee
Consumer Technology Workgroup
Transcript
November 22, 2013**

Presentation

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thank you. Good morning everyone, this is Michelle Consolazio with the Office of the National Coordinator. This is a meeting of the Health IT Standards Committee's Consumer Technology Workgroup. This is a public call and there will be time for public comment at the end of the call. As a reminder, this meeting is being transcribed and recorded, so please state your name before speaking. Also as a reminder, if you aren't the one speaking, please mute your line. I'll now take roll. Leslie Kelly Hall?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Russ Leftwich? Brian Ahier?

Brian Ahier – President – Advanced HIE Resources

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Christine Bechtel? Brian Carter? AJ Chen? John Derr?

John F. Derr, RPh – Health Information Technology Strategy Consultant – Golden Living, LLC

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Tonya Dorsey? David Harlow? Arthur Henderson?

Arthur R. Henderson – President – Affinity Networks, Inc.

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Susan Hull?

Susan Hull, MSN, RN – Chief Executive Officer – Wellspring Consulting

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Liz Johnson? Tom Jones? Mohit Kaushal? Holly Miller? Marcia Nizzari?

Marcia Nizzari, MS – Vice President Engineering – PatientsLikeMe

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

John Ritter? Anshuman Sharma? Fred Trotter? Kim Nazi? Susan Woods?

Susan Woods, MD, MPH – Director of Patient Experience, Connected Health Office – Veterans Health Administration

Here.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

And are there any ONC staff members on the line?

Ellen V. Makar, MSN, RN-BC, CPHIMS, CCM, CENP – Senior Policy Advisor – Office of the National Coordinator

Ellen –

Mary Jo Deering, PhD – Senior Policy Advisor, Office of Policy and Planning – Office of the National Coordinator

Mary Jo Deering. I'm sorry, Mary Jo Deering.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

And I heard Ellen Makar as well.

Ellen V. Makar, MSN, RN-BC, CPHIMS, CCM, CENP – Senior Policy Advisor – Office of the National Coordinator

That's right.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

And with that, I'll turn it back to you Leslie.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Super, thank you Michelle. And I appreciate those of you who could join us today, at this Friday before Thanksgiving. I know that takes extra effort and I very much appreciate you. So, in the – I'm sorry, did someone just join?

David Harlow, JD, MPH – Principal – The Harlow Group LLC

This is David Harlow.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Great. Hi David. So, with that, let's get going and I'll be mindful of everyone's time. Next slide please. Next slide. Oh, before I move off of that, I would like to welcome, although Russ was not able to join us today, Russ Leftwich has generously agreed to Co-Chair this with me and I'm very excited about this. Russ brings an expertise both as a physician and a clinical informaticist, is very, very active in the longitudinal care planning and is eager to participate. So, I'm very, very happy and honored to have Russ Co-Chair this meeting. So, you'll be hearing from both of us in the future.

We have asked the group also to let us know how you might want to continue. We see this phase of our work coming to an end once our recommendations have been made going forward on – for Meaningful Use Stage 3 consideration, but we see work yet to be done in the future and are asking the members of the committee about their interest to go forward, continuing our efforts. And so we will – have heard from many of you, would encourage to hear from more of you and we'll be reconfiguring this group probably in the January timeframe, so that we're emphasizing some up and coming work, the emphasis on care planning, for instance, perhaps consumer vocabularies and other issues. So, look forward to hearing from you and your continued interest. Please email both me and Michelle and is that the correct approach Michelle, if there's continued interest in going forward in this next phase of work.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Yes, that would be perfect. Thank you, Leslie.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Okay, super. Next slide please. So today we're going to discuss our draft recommendations and a little bit of the Standards Committee feedback. And I would please ask John Derr to also help in commenting on that feedback today. We're also going to discuss if we or should we have anything specific with regard to mobile devices and VDT. And then take – begin discussions on consumer vocabularies and then open for public comment. So next slide please.

So one of the things that we all I think struggled a bit with was evaluation of readiness. This was a topic that was part of the Standards Committee feedback, those members on our committee as well as in the session itself. Now if you recall, we all started with a bias to use existing standards where possible and reframe them under the patient or consumer. And that both brought the good and – we inherited both good and bad with that decision, but mostly it gave us an opportunity to consider standards at a different level of maturity than if they were new. So if you recall the direction that we received from Dixie Baker, who was part of the NwHIN team. We heard that when a standard is mature in the provider world, even though it is being used in a new way for the consumer or the patient, that that combination of perhaps mature and new would end up somewhere in the middle.

So we have gone forward with an assumption that using these existing standards we are somewhere in the middle of the maturity adoption. Those NwHIN reports that we received from our technical expert often puts them in the middle or beyond, but I think there was some agreement that based upon these existing standards that we've put forward, we were somewhere in the middle. And I offer up and ask John to comment if I've gotten that correctly or other than the team, who also listened in to the call, whether I've interpreted that correctly. John, are you still with us?

John F. Derr, RPh – Health Information Technology Strategy Consultant – Golden Living, LLC

Yeah, I was on mute and I – my phone –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Okay.

John F. Derr, RPh – Health Information Technology Strategy Consultant – Golden Living, LLC

Yes, you're absolutely right that we are in the mi – yup.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

So I think that's where we ended up. I'm curious to see if Michelle or other staff members that were participating if I've also reviewed that appropriately.

Ellen V. Makar, MSN, RN-BC, CPHIMS, CCM, CENP – Senior Policy Advisor – Department of Health & Human Services

I agree this is Ellen.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Okay. Super. So I think that gives us an opportunity to go forward with pretty good, I guess, foundation in our recommendations. Next slide please. So to recap, we had put forward for consideration some assumptions that we would be using a common meaningful use data set standards and vocabulary, that we would be making these recommendations in somewhat of a device and technology agnostic way. We would assume that things like responsive design would be part, but I'd like to put that on hold for a moment.

So in recap, we're looking forward to the HL7 care team roster that really begins to set the stage for new participants in HIT. And if you recall this standard Russ Leftwich presented to us and it was this standard has been harmonized across the Consolidated CDA and has been harmonized at the DAM level, and I mean that in the acronym point of view and not the blasphemy. But this particular care team roster has also been harmonized with CDISC, which is a research organization. So we had an opportunity to say, hey, these participants now being added to HIT could potentially cover patient-generated health data as well as future uses of things like patient-reported outcomes and research, as well as care planning, that this was a foundational item. We did not receive any pushback on this in the meeting itself.

We also recommended the Direct standard – the Direct standard for use of patient-generated health data for inbound as one possible standard. Concerns that have been raised were around the maturity of this for patients, yet there is current work going on and I invite the team to comment about Direct and use of patient directories in the future. And that work is being established and you recall that Direct is named in Meaningful Use 2 standards for view, download and transmit with providers, and that much of the work being discussed around directories for providers would apply, we hope, to patients in the future. So there was some discussion about the readiness of this, but acknowledgement that those things are being worked out – have to be worked out for Meaningful Use 2 for providers and we hope that we can inherit that work for patients going forward. John, do I have that – was there any other comments that you'd like to add, or anyone else that was in the Standards Committee meeting?

John F. Derr, RPh – Health Information Technology Strategy Consultant – Golden Living, LLC

No, we really – they discussed a little bit more just on its readiness, but Direct – I mean, we're using that already so, I think that was a good decision.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Okay, then –

Brian Ahier – President – Advanced HIE Resources

This is Brian; I'd like to comment on this.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Please.

Brian Ahier – President – Advanced HIE Resources

Actually a great deal of work being done, as you said, in terms of Stage 2 Meaningful Use and provider-to-provider communication using Direct. And I think much of that work will be able to be leveraged for provider patient communication, as well as there's a couple of payers, including some government agencies that are interested in payer to patient communication. One exciting thing that's going on right now is there's some open source work being done on some applications that will allow look up across provider directories, using – plus. And so expect over the next few months, some really exciting work and capabilities to be made available. And so I'll certainly keep you informed, because I think it does – it will certainly be something that we can leverage, in terms of patient directories as well.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

That's great news. I also saw some of those email chains this last couple of weeks about that work and it does sound very exciting and very applicable. There is a bias within Direct Trust to look at the patient as just simply another participant and that the good work being done both in open source community and others are doing so with an assumption that we are all on equal playing fields. And there doesn't have to be this separate but equal approach, but more a technology approach across all participants. Did I characterize that correctly Brian?

Brian Ahier – President – Advanced HIE Resources

Yeah, I would – think so, I mean, from a technology perspective; it actually doesn't matter if it's a provider, a patient, a payer, an organization, an individual or even a machine. So, I think trying to look at it in ter – I was just – the only reason why I say leverage for provider to patient communication and other types of patient centric communication is because right now there's not a lot of activity, in terms of using Direct, to communicate with patients. There's some, but there's not as much as I want to see and I think that's going to change dramatically over the course of the next few months.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

That's great, we'll look forward to getting feedback and updates as you have them, Brian. Thank you. So moving to the next area, we did recommend the Consolidated CDA. And I think recommend is too strong, this was an update to the Standards Committee and getting their feedback, our next phase is a joint recommendation with the consumer policy group into the Meaningful Use Committee and then I think we go through the normal process of reconciliation and so forth. And perhaps – Michelle, I can ask you at the end of the call to review the process steps that we're going to go through next, if that's all right?

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Sure.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Great. So on the Consolidated CDA we had positive feedback. There was some discussion about making sure that as we go forward with these, we have patient specific testing criteria on the Consolidated CDA testing certification. But other than that, there seemed to be a good deal of support. Then moving beyond that, we looked at the Continua standard, there was not a lot of discussion at the Standards Committee, but there still is that tension between consumer product based standards versus provider products based standards in this area. One of our recommendations, if you recall, is that we felt that when data goes inbound, that information is more likely to be around provider-based standards, but data coming outbound could be much more around consumer standards.

So one of the discussions was that provider-based standards of the devices that would be considered are devices that might be more often provider prescribed, and we don't really know how to define that yet. So there's some discussion I think we still need to have around this, but it's more about the policy adoption of this than it is the viability of the technical standard. There's where I think the actual rub is, is the actual policy implications versus the technology. And I offer that up as a question as much as a statement to the other members of the Standards Committee and others that listened in on that call. John, do I have that correct?

John F. Derr, RPH – Health Information Technology Strategy Consultant – Golden Living, LLC

Yes, you do.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

All right. Super. So, with that, let's go to the next slide. So, here is where we are landing is that ONC should consider the Direct transport standard for secure messaging and data from devices. And this is actually not just data from devices, I think we had edited that, but the concerns we had is devices can go a lot of different ways beyond Direct and we don't want to name just one transport standard, because there are many. And that we should consider the HL7 care team roster, that we should consider the Consolidated CDA for structured and unstructured questionnaires. And again, the device data can be both transported on Direct or not and can include Consolidated CDA or not and there are many standards within that. So I would offer we had a period there. And then ONC again, consider Continua standard for device data. So I'll resubmit this up to the group for discussion, are there any other concerns that we would like to raise at this time?

Okay. Next slide please.

David Harlow, JD, MPH – Principal – The Harlow Group LLC

I'm sorry this is David Harlow.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yes.

David Harlow, JD, MPH – Principal – The Harlow Group LLC

I forgot about the mute button. I wanted to ask whether those sta – those recommendations include anything specific regarding mobile access?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

So we need to discuss that. One – we had a variety of opinions and one was that responsive design today is largely – development is largely going on that's agnostic of device. And that whether it's a surface, a tablet, or a mobile, that there are other principles of design that are being adopted by the industry and that there wasn't specific standards that needed to be called out. Now I'm putting that out as a question for the group to discuss is there a compelling need to name standards for specific mobile use or do we believe that's an industry response.

David Harlow, JD, MPH – Principal – The Harlow Group LLC

My personal reaction is that parts of the industry are more responsive to the notion of having mobile responsive design than others. I mean, in other words, some websites work on mobile and some don't.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Um hmm. Is that a question of market or standard imposition that needs to help it?

David Harlow, JD, MPH – Principal – The Harlow Group LLC

Well I guess in the first – looking at other websites, it's a market issue, but if you want to promote accessibility to patients, I forget the percentages, but there's a growing number of people who access the web only or primarily for mobile. If there isn't mobile accessibility for the information that we're talking about that means it's inaccessible to a certain percentage of people.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Um hmm.

David Harlow, JD, MPH – Principal – The Harlow Group LLC

Yes the market is moving in that direction, but I don't know if we need to identify a standard, but we need to identify a requirement, I think.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

So what kind of a requirement would that be, mindful that our task is standards versus policy, what would we recommend? Is it something along the lines of we encourage the use of responsive design and device agnostic development? Or is that something that we would name a standard, and I – Brian, you're very much involved in, I know, much of the open source community and some of – do you have an opinion about this?

Brian Ahier – President – Advanced HIE Resources

No, not specifically. I think – well, I think just one thing that we don't want to do is tightly constrain the standards, especially when we're thinking about – we don't want to stifle any innovation.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Right.

Brian Ahier – President – Advanced HIE Resources

And so I agree with the comments that have been said already.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

All right, so would we –

Arthur R. Henderson – President – Affinity Networks, Inc.

This is Arthur Henderson.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yes.

Arthur R. Henderson – President – Affinity Networks, Inc.

I just want to make sure that when we say mobile, that we are not just limiting it to Smartphone, because as was pointed out, the lower your socioeconomic level, while you may have a phone, that phone may only have SMS capability, text messaging capability.

M

Good point.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yeah, we did get some testimony, I'm not sure which group it was that reported that the pay as you go phones are now about 60 percent or more of them are Smartphones, so we're seeing that trend, but I agree with you, we have to be mindful of not stifling innovation and perhaps also not limiting particular uses. So, does the group then feel comfortable that we are either silent on mobile device standards or that we are recommending some sort of statement that says we encourage design and – encourage design that includes – that is agnostic to device type and that we will revisit mobile device standards as they mature in healthcare. Is that a statement we would be comfortable with or should we be more prescriptive?

David Harlow, JD, MPH – Principal – The Harlow Group LLC

This is David again and that works for me, keeping in mind that we're talking about standards. I wouldn't want to have a prescriptive standard for mobile accessibility at this stage of the game.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yeah, okay. Does the group feel comfortable with that? Susie?

Susan Hull, MSN, RN – Chief Executive Officer – Wellspring Consulting

This is Susie, I was going to say yes, I concur and I think it's important to make a statement about it just because of the proliferation in the marketplace; we're beginning to precede that.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Okay. That sounds fair enough. Yes?

Susan Woods, MD, MPH – Director of Patient Experience, Connected Health Office – Veterans Health Administration

This is Sue Woods. I agree, it's not a standard but bringing in the issue of making sure that it can reach across the population and encourage. My question is, this issue is not unique to patient facing data, are there other workgroups, I would imagine, clinical information systems are addressing these issues as well –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

I would ask – go ahead.

Susan Woods, MD, MPH – Director of Patient Experience, Connected Health Office – Veterans Health Administration

So my question is, are there other groups that – or the Standards Committee that have looked at mobile in general, across all clinical information system technology, because it's not unique to patient.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Agreed and I have not seen yet a mobile-specific standard recommended. And I would ask ONC staff if they recall any in the other teams?

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

This is Michelle. I haven't been working with Standards Committee for too long, but since I've been involved, I haven't heard of any workgroups working on the topic. Mary Jo, I don't know if you know if people have in the past, but as of now, nobody else is working on it.

Mary Jo Deering, PhD – Senior Policy Advisor, Office of Policy and Planning – Office of the National Coordinator

This is Mary Jo and I think you're all correct because remember what the Standards Committee is looking at is requirements for certified EHR technology. And right now, there are – they have, in Stage 2 already, redefined that to include a modular approach, but these are modules of computers that could together be considered the – acceptable for fulfilling MU requirements. And that's a longwinded way of saying that since the Incentive Program is around the use of certified EHR technology, they'd have to move broadly to consider mobile devices and how they fit in to that definition of a certified EHR technology

Ellen V. Makar, MSN, RN-BC, CPHIMS, CCM, CENP – Senior Policy Advisor – Office of the National Coordinator

This is Ellen, isn't FDASIA working on that as well?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

So FDASIA is working on the – what the role is of oversight between or among federal partners like ONC and FDA, and where the line is within a mobile device that is considered a medical device versus an HIT device. And I think they have made a recommendation that's a risk-based assessment of mobile use to define or to determine medical device use. So, given all of that, it sounds to me that just simply stating a – making a statement of encouragement that mobile be considered or that we hope that there is device agnostic approach for consumers specifically, might help spur efforts in other areas, but mandating that either in our area or others seems premature.

Susan Hull, MSN, RN – Chief Executive Officer – Wellspring Consulting

And then Leslie – Susie Hull again. I think as the frame for 2014 is developed for this workgroup, I think it's something we need to keep on our radar, because I think the lines are going to start to blur fairly quickly as more and more innovators and even EHR companies expand the capability for patient-generated health data through mobile devices through other ways. That we need to be, I think, monitoring this in some way to see when there is more work to be done here.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

That's great advice and then I also harken back to the earlier comment about text messaging, which we are beginning to see work in that area, in other parts of the industry. So let's – we'll keep that on our radar and revisit that as we go forward.

Brian Ahier – President – Advanced HIE Resources

Yeah, this is Brian. I would certainly encourage us to do that because I think that we're on the cusp of probably some pretty broad innovations in this space, and so the technology could, in some degree, help inform the policy considerations.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Great. Thank you. All right, next slide. So one of the things that – let's see, before we get there, I think we were going to talk about vocabulary, is that this slide or the next slide. Oh sorry, thank you. Okay, then go backwards. All right. So one of the things that we wanted to consider was – and has also started to talk about is really an emphasis on collaborative care. We heard very loud and clear from the policy side of the consumer group that care planning was a very strong recommendation going forward. How do we plan and how do we move towards a collaborative care environment, which is very consistent with the Triple Aim and the long-term goal of meaningful use and the ONC.

We recognize in our group, as well as others, that the idea about provenance, versioning, reconciliation, data governance and curation was a big deal, and have put forward a recommendation that this be considered, not just for patients, but also for all care team members. John often reminds us of the long-term post-acute care participants. We have heard from MaryAnne Sterling and others about caregiver participation. we've heard from Russ around the longitudinal nature of care planning; so this is an opportunity for further work. And just this last week in a meeting that Doug Fridsma was – actually was at the AMIA meeting, there's a group starting to discuss this, the how can we launch this work? So I think there's huge momentum there and I applaud this group for bringing that broad need up.

We also stated that ONC should consider creating a process to align consumer product and provider standards. I do think this group has done a great job of using existing standards and putting them forward, but I think to Brian's point, we will see technology on the consumer side starting to influence healthcare. And to constantly be mindful that this is not just the provider world accepting the consumers, but the consumer world accepting the providers into it. So, alignment will be an important continuation.

We also heard – AJ Chen on this group that we need to consider aligning the Blue Button and an API approach to accommodate patient-generated health data in the future. And I refer to this as turn the Blue Button upside down. And then also that we need to look at the Trust Framework and expanding that in newer technologies. And we should ask the Standards Committee to prioritize consumer vocabularies to support wider consumer, patient and family engagement. And the next slide will discuss that.

John F. Derr, RPh – Health Information Technology Strategy Consultant – Golden Living, LLC

Leslie, this is John Derr.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yes.

John F. Derr, RPh – Health Information Technology Strategy Consultant – Golden Living, LLC

On point number one, did – have we looked at what the longitudinal care committee is doing under S&I Framework, because we're really looking at –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yes, that's –

John F. Derr, RPh – Health Information Technology Strategy Consultant – Golden Living, LLC

– longitudinal and that maybe we can incorporate this into that once –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yes, in fact what largely informed that was when Russ presented to us on the longitudinal care team work that had been done. So this is really an expansion of that. So next slide. So one of the things we were tasked with is are consumer vocabularies ready for prime time? Is there – is this an emerging work? Is this something we can land on? So examples, we heard from in the Standards Committee was the recent donation of Kaiser Permanente to NLM of their portion of their consumer vocabulary. We hear often of organizations that have mapped medicine to consumer technology vocabularies, now we're considering then, does there need to be a vocabulary standard to get consumer terms translated into medicine and back up? So I'd like to open this up for discussion in the group and find out what kind of opportunities there are in this. Is there maturity in this as yet and what, perhaps, recommendations the group might have.

Marcia Nizzari, MS – Vice President Engineering – PatientsLikeMe

Hi, this is Marcia Nizzari from PatientsLikeMe. Sally Oken, who's quite well known as a person who really promotes the patient voice has done a tremendous amount of work with our patient-generated data mapping patient terms on to SNOMED and – other vocabularies, and I'm sure that she – we'd be more than happy to share that information for whomever would be interested in looking at that. I think that's available probably in spreadsheets, I mean, very easily accessible. Would that be of help?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

I think so. I think it may be a good opportunity for this team to hear about different consumer organizations, like PatientsLikeMe or like Healthwise or Kaiser and others, Apelon, IMO and others to see what is the current state of affairs and status of consumer vocabularies both in the public domain or proprietary and how could we inform a larger need. I think that would be worth some discussion. It – PatientsLikeMe has about 250,000 or more, yeah 250,000 patients that they've used to help map this data and I think it would be important to hear from many of us in this space, to see what could emerge. Are there any on the team that feel there is a known consumer vocabulary that we could discuss or are we still in this sort of formative stage?

Susan Woods, MD, MPH – Director of Patient Experience, Connected Health Office – Veterans Health Administration

This is Sue Woods. There's an Open Access Collaborative called the Consumer Health Vocabulary Initiative. I don't know if people are aware of it. It's led by a woman named Jing Zeng, she's at the University of Utah. She works with us a little bit at the VA. I was not able to get to her session at AMIA, but I think she would have probably one of the leading edge views. My suspicion last time we connected with her, probably six months ago, is that it was still in the forming stage. But there is a – there's an online, it's called ConsumerHealthVocab.org.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Great. That would be wonderful, so perhaps we could look at that after the first of the year, gather both University of Utah, PatientsLikeMe and others, Healthwise, IOM, Apelon, others to participate in a think tank meeting around consumer vocabularies. So, that's really good news that all of these things are starting to come together, but I agree that it's very formative right now and that it be premature to recommend any standard on consumer vocabulary.

Susan Hull, MSN, RN – Chief Executive Officer – Wellspring Consulting

Leslie, Susie Hull, I have two other things to add to the – if we're going to do a think tank or review. One is, this is an effort that's been around harmonizing semantic interoperability with patient-generated health data and it started probably in 2011 or 12 with Paul Estabrooks, Maureen Boyle, and Russell Glasgow. They convened a number of – an expert panel through several sessions to look at what would be the minimum data set that would be needed to harmonize patient-generated data into the EMR? And they're not nece – I don't know what they've done in terms of consumer vocabulary, but they have done 18 pilots with this and it's called The More Project. I haven't checked in with them in a little bit of time, but it would be good to see where they are.

The other thing that other's may be more familiar with than I am, but Health Language, sometime back actually took their ICD-10 kind of language and turned it into a consumer friendly terminology. And it would be good to see where they are with that work and others who have done that. I also really like the work that PatientsLikeMe has done, and I think that would be helpful to see it, because I think we have a chance early on to get some – to do some work so that we don't end up with so many different ways to think about this.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yeah. So I agree, I think there's emerging work and it would be great to get a current state and inventory and then talk about how collaboration can occur. If you have the specifics on this More Project, if you can get back to Ellen or Michelle or Mary Jo, then we can all start to maybe gather a group of people we want to reach out to inform this. That's exciting news. I do think that the stars are starting to align all of this, but we're still in that constellation stage.

Mary Jo Deering, PhD – Senior Policy Advisor, Office of Policy and Planning – Office of the National Coordinator

Leslie, this is Mary Jo. I do recall at the Standards Committee meeting that there really was some interest in consumer vocabularies and I – while I'm – I can't remember whether there was a specific follow up action, I came away with a distinct impression that the committee would like to start looking at this. There is a vocabulary subgroup under the Clinical Operations Workgroup –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Um hmm.

Mary Jo Deering, PhD – Senior Policy Advisor, Office of Policy and Planning – Office of the National Coordinator

– and so this might be a perfect joint effort to bring this forward, since – especially since you may not want a standalone standard, but certainly having these terminologies available. So, I think you could get a lot of traction in at least one other workgroup of the Standards Committee.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

That would be great because Jamie Ferguson leads that committee and he was very much responsible, I believe, for the Kaiser donation. So, this would be a great opportunity for alignment in those two groups, so thank you for that reminder.

David Harlow, JD, MPH – Principal – The Harlow Group LLC

This is David Harlow. As we're discussing this, I've pulled up a couple of references online that I had vaguely remembered. The National Library of Medicine has a medi thesaurus project and there's been some published work extending the medi thesaurus from clinical dictionaries and terms to the Dictionary of American Regional English for certain disease categories. And I don't know how widespread that's been or whether that might be a useful starting point.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Well that's great, thank you for that. So it looks like we've got some good work ahead on that area. As those of us come across other ideas for consideration, please make sure that you get those to me, Russ, Ellen, Michelle and Mary Jo, and we can make sure that that's part of our consideration. Super. Other comments on vocabulary, otherwise we'll go to the next slide. Okay, next slide please.

Ellen V. Makar, MSN, RN-BC, CPHIMS, CCM, CENP – Senior Policy Advisor – Office of the National Coordinator

That was the last slide.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

That's the last slide. Okay.

Ellen V. Makar, MSN, RN-BC, CPHIMS, CCM, CENP – Senior Policy Advisor – Department of Health & Human Services

Yeah.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

So I guess the – at this point in time I'd like to thank the group and say Happy Thanksgiving, and also make sure that if you have interest in continuing after the first of the year in some of these new topic areas, please get your level of interest to Michelle and Ellen. And with that, I would like to – yeah.

Brian Ahier – President – Advanced HIE Resources

Leslie, this is Brian. Could I just throw in one additional comment and that is, the month of giving thanks here, I especially want to give thanks and call out the great work that Mary Jo Deering has done with the ONC and wish her all of the best.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

That I am so thankful that you brought that up. I echo those comments and I would like to add that Mary Jo has been a constant reminder that healthcare can't happen without the patients. She has been tirelessly involved in consumer and patient advocacy in every role that she's been in, and I am honored to have been serving with you Mary Jo.

Brian Ahier – President – Advanced HIE Resources

Here, Here.

Mary Jo Deering, PhD – Senior Policy Advisor, Office of Policy and Planning – Office of the National Coordinator

Well, my word. My goodness, thank you. Thank you all very much. It's been for me really wonderful to see this workgroup and the consumer workgroup on the policy side come into being this year. And I think you're just beginning to fill your sails with a good wind and I think that a lot of good work is going to emerge. And I'm really appreciative of the people who volunteer their time to make it happen.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Speaking of volunteerism, Mary Jo, as you leave the government, we hope that you – and encourage you to volunteer in service.

Mary Jo Deering, PhD – Senior Policy Advisor, Office of Policy and Planning – Office of the National Coordinator

Well, I did tell ONC that I would put my name in their application database to serve on workgroups.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Wonderful. So with that, I would like to say thank you all for participating and we'll open it up for public comment and Happy Thanksgiving.

Public Comment

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Operator, can you please open the lines?

Ashley Griffin – Management Assistant – Altarum Institute

If you are on the phone and would like to make a public comment, please press *1 at this time. If you are listening via your computer speakers, you may dial 1-877-705-2976 and press *1 to be placed in the comment queue. We have one public comment. Deb, go ahead.

Debra Farmer Warwick

Yes. Good morning. I've just been thrilled to find this meeting this morning. I'm in California, so it's a little early for me, but I just discovered this meeting yesterday –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

And you are?

Debra Farmer Warwick

I am Deb Warwick. I am a patient and have been involved with the project since 1989 with the revisions – beginning with the revision of the International Classification of Impairments, Disabilities and Handicaps. It's now called the ICF, the International Classification of Functioning Disability and Health and I've been involved with that very much to bring the patient and caregiver voice to the table. I started out with special education and designing tracking systems for children with disabilities from birth through when they exited school and expanded that into the idea that we should use something along those lines for the patient voice and caregiver voice for a lifetime.

So I would like to thank you all for your work, see how I can get involved in this project more and recommend that the ICF be considered as a vocabulary with this project that you're on. There are quite a few other ICF colleagues that have been involved with the health standards, one we're about to lose is Marjorie Greenberg at the National Center for Health Statistics, she's retiring on November 30, but she sat in on a lot of the committees and was a major player with the World Health Organization North American Collaborating Center. So I am very passionate about what you're doing and would very much love to be involved. As a patient myself, I have a lot of times encountered difficulties in speaking with my physicians and getting the appropriate language put in my health records. So –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Thank you very much for that comment and I would encourage you and anyone listening to this call that on the HealthIT.gov website, there is an opportunity for people to volunteer and provide application to be considered in workgroups going forward. And I thank you for the work that you've done Deb and the passion you bring and encourage all to sign up and volunteer, because the more the merrier.

Debra Farmer Warwick

Wonderful. Has the ICF been brought up in this committee yet at all?

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

I'm sorry, public comment is limited to three minutes and we actually don't need to respond to public comment, it's purely to comment. Sorry about that Deb.

Mary Jo Deering, PhD – Senior Policy Advisor, Office of Policy and Planning – Office of the National Coordinator

But perhaps Michelle, you could tell her how to submit an email comment, just so that we capture everything for the record.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Sure.

Mary Jo Deering, PhD – Senior Policy Advisor, Office of Policy and Planning – Office of the National Coordinator

Because she – anyone is able to submit emails to ONC to be sure that their input is received.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

If they're on the webinar, they can just submit a comment through the public webinar. I don't know if you are, but –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Great. All right, any others?

Ashley Griffin – Management Assistant – Altarum Institute

We have no further public comments.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Great. Well Happy Thanksgiving everyone and we look forward to –

AJ Chen, PhD – Chair, Data Committee – National Partnership for Action Region IX Health Equity Counsel

Leslie, Leslie –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yes?

AJ Chen, PhD – Chair, Data Committee – National Partnership for Action Region IX Health Equity Counsel

This is AJ.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Hey.

AJ Chen, PhD – Chair, Data Committee – National Partnership for Action Region IX Health Equity Counsel

Hello?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yes, yes?

AJ Chen, PhD – Chair, Data Committee – National Partnership for Action Region IX Health Equity Counsel

Sorry, I joined late and I later found out that I actually used a different line that you cannot hear me. So now I switched to the line that I can actually speak. But I heard half of your – most of your discussion already today. So one – I have one – a couple of information about the voca – consumer vocabulary. The company that I work for previously Healthline Networks is a leader in the consumer technology space and they – I think they have one key asset they have is the consumer oriented vocabulary. I think they probably have the largest consumer vocabulary in – for healthcare, and that's one of the main reasons that most other big companies like IBM, Microsoft Health, Yahoo Health and I think AARP and many others are actually using their taxonomy, which has that consumer vocabulary. So I just –

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Super.

AJ Chen, PhD – Chair, Data Committee – National Partnership for Action Region IX Health Equity Counsel

– wanted to mention that this is also a company that you could consider when you look into – yeah, go ahead.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

I'm glad you mentioned that AJ because I think that all of these comments that we're receiving from the group and the public reminds us that there's good work being done and there's an opportunity for harmonization and consideration as we go forward. So thank you for that, and I'm sorry you ended up on the wrong line. So with that, I think that we can adjourn and thank you very much, all of you, for your participation in this workgroup and have a great Thanksgiving.

Mary Jo Deering, PhD – Senior Policy Advisor, Office of Policy and Planning – Office of the National Coordinator

Thank you Leslie.

Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator

Thank you Leslie. Happy Thanksgiving everyone.