

U.S. Core Data for Interoperability Task Force

Transcript
March 5, 2019
Virtual Meeting

Members/Speakers

Name	Organization	Organization Type
Christina Caraballo	Audacious Inquiry	Co-Chair
Terrence O'Malley	Massachusetts General Hospital	Co-Chair
Tina Esposito	Advocate Aurora Health	Member
Valerie Grey	New York eHealth Collaborative	Member
Ken Kawamoto	University of Utah Health	Member
Steven Lane	Sutter Health	Member
Leslie Lenert	Medical University of South Carolina	Member
Clem McDonald	National Library of Medicine	Member
Brett Oliver	Baptist Health	Member
Steve Ready	Norton Healthcare	Member
Sheryl Turney	Anthem Blue Cross Blue Shield	Member
Stacy Perchem	ONC	ONC Staff
Adam Wong	ONC	ONC Staff
Johnny Bender	ONC	ONC Staff

Operator

All lines are now bridged.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

All right, thank you. Good morning, everyone, and welcome to the second iteration, if you will, of the USCDI Taskforce. Just as a reminder, this taskforce, while similar in membership, is slightly different in its scope, in that this group is charged with providing recommendations in response to ONC's proposed rule for the 21st Century Cures Act. So, with that, you'll see some of the familiar players, but we will certainly have a different charge and scope, which the co-chairs will walk us through very shortly. So, I'll call the meeting to order, starting with roll call. Christina Caraballo?

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

Here.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology -</u> Designated Federal Officer

Terry O'Malley?

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Here.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Steven Lane?

Steven Lane – Sutter Health – HITAC Committee Member

Here.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Brett Oliver?

Brett Oliver - Baptist Health - HITAC Committee Member

I'm here.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Sheryl Turney?

<u>Sheryl Turney – Anthem Blue Cross Blue Shield - Member</u>

I'm here.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Leonard? Not yet? Ken Kawamoto, I believe, is absent. Clem McDonald?

Clem McDonald - National Library of Medicine - HITAC Committee Member

Here.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Valerie Grey?

Valerie Grey - New York eHealth Collaborative - Member

Here

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Tina Esposito?

<u>Tina Esposito – Advocate Aurora Health – Member</u>

I'm here.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Brady? Not yet. And Andy Truscott? Okay. With that, I will hand it over to our co-chairs, Christina Caraballo and Terry O'Malley, to kick us off. Christina or Terry?

Christina Caraballo – Audacious Inquiry – Co-Chair

Okay. Terri, did you want me to go through the agenda and get started?

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Sure. Go ahead. I was on mute. Go ahead.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

Okay. Totally up to you.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Fire away.

Christina Caraballo – Audacious Inquiry – Co-Chair

Okay, sounds good. Well, thank you all for joining. Today we are going to just do a quick overview of our membership and then go right into reviewing what is in the new U.S. Core Data for Interoperability, as well as our charges and work plans. So, our first charge is going to be to review the USCDI Version One Data Elements, and the second will be to look at the draft promotion model. And then we are hoping to go ahead and get into our discussion on the patient demographic elements, which will make more sense as we kind of move through the agenda. So, let's go on to the next slide.

So, this is a snapshot of our membership. We have a lot of the same members from our first one. So, welcome back for round two. I know Terry and I and our ONC chair leads, Stacy and Adam, are all really excited to get this back started up again. So, you'll notice on our membership this round that we have all HITAC members. With that being said, we do plan on bringing subject matter experts in as needed. And ONC is already working on a list of identified subject matter experts based on the agenda items and our charge. Terry, did you have anything else to add to that?

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

No, I think that sounds great. Other than, really, thank you all again for putting your lives on hold to be part of this little episode. So, thanks again. Really appreciate it.

Christina Caraballo – Audacious Inquiry – Co-Chair

Okay, so let's go ahead and get right into it. Let's move on to the next slide. So, just a quick overview. I do know that we had the – at our larger committee meeting, we had a wonderful overview of all of this. But with how big everything is with the new NPRM and our four taskforces, we figured it would be good to just recap on some of the slides that ONC has already put together. So, as a reminder, ONC is proposing to replace the Common Clinical Dataset definition with the U.S. Core Data for Interoperability Standard. So, it is becoming a standard in this proposed rule. And we are looking at version one today.

So, the goal here is to really look at increasing the baseline data to be exchanged, commonly to improve interoperability and data exchange. So, within the USCDI, as I stated, we have the Common Clinical Dataset, and then the proposal of a few more data classes. And those include provenance, clinical notes, pediatric vital signs, and address and phone number. And then, the first set that we're looking at is really under our task one, to look at the data elements of these four additional data classes. The second part of the USCDI standards is the annual update schedule, which we will be reviewing as part of our task two, under the promotion model process. So, let's go ahead and move on to the next slide.

So, our specific charge for phase one is to review these newly specified data elements under the proposed USCDI version one, providing recommendations specifically on the inclusion of state of provenance, clinical notes, pediatric vital signs, and then data – or sorry, address and phone number under demographics. And then also, looking at any missing data elements within the proposed data classes, or data classes that are already in existence.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

And Christina, if I could add something, we're pretty limited to what these categories are. I mean, we're not adding new categories. That's beyond our scope. We can address these five different things. Of course, missing data elements is sort of a broad category. But within each of these categories, if we want to add new data elements, they need to be – and I think Steve used the phrase a logical extension of the elements in that data class. We couldn't suddenly go off and add lab data to provenance. So, there has to be some logical connection between what's already in the data class and what we're proposing. But if it's a reasonable fit, then we won't get a lot of pushback. So, just kind of keep that in mind. There are sort of limits to how far we can go. That's the end of the editorial comment. Thanks, Christina.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

No, excellent, excellent point, Terry. And that actually leads really well into the next slide. This is just kind of a visual of the previous slide. It's all in one snapshot. If you look at the highlighted or purple, then those are the new data elements that ONC is seeking recommendations for that we're really going to start our focus on at the beginning of this taskforce. And then the ones in blue are the data classes that are already in existence within the Common Clinical Dataset. And to echo Terry, those are ones that we'll look at less. However, one thing we may dive into is looking at some of the data classes already in existence that might need a little more flavor. For example, we have care team members, but no data elements under that. And is that something that, if we have time, we would want to look at some of those others to review? But again, we're going to stay very focused on the highlighted sections as the key part of our charge.

So, then moving on to the next slide, just is basically a breakdown of what we are looking at under provenance. They're looking at including – this is a new one – with three proposed data elements, including author, author's timestamp, and author's organization. And ONC is really requesting that we comment on the inclusion of these three and any additional. Moving on to the next slide.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

We're gonna talk about these at the end?

Christina Caraballo – Audacious Inquiry – Co-Chair

Yeah. We are. Today we're going to specifically talk about the patient demographics because we thought that would be a good one to start with. And then once we get through this, we'll show you a timeline of when each will be talked about and our kind of plan for gathering information and discussion around them.

Clem McDonald - National Library of Medicine - HITAC Committee Member

Could I just raise a confusion? So, the USCD One thing that's on the web is different than what you've presented here. Not much, but it's clearer, and I really think that we shouldn't have two versions floating around.

Christina Caraballo – Audacious Inquiry – Co-Chair

Clem, I don't know what you're referring to.

Clem McDonald – National Library of Medicine – HITAC Committee Member

There is a USCD One representation very close to this on the ONC website, and it's not the same. It has a little more detail. And I think we shouldn't be using this one. We should be using the one on the website, which I think is more recent.

Christina Caraballo – Audacious Inquiry – Co-Chair

Okay. Well, we'll take note to follow up on that. I know these were slides that ONC has been using, so my assumption was that they were the most recent. But we can definitely check.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

It's a little clearer. It says just a little more.

Christina Caraballo – Audacious Inquiry – Co-Chair

Okay. And I'm sorry, I was gonna call on Sheryl. Was that what you were gonna ask me, Lauren?

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

Yeah. This is Sheryl. I don't know. I actually had a question about the provenance, because with the identification of those attributes, what I wasn't clear on – and again, I haven't yet found this in my read of the rule – but are those provenance attributes going to be added for a single reference, or can multiple references be included? I do think when we get to that discussion, it should not only be about the attributes, but also the way the attributes would be used, because that's going to be material in terms of how and whether or not they're sufficient. I don't know if this group agrees with that, but because we're gonna be dealing with things that have been dealt with in blockchain and other things that they come forward, which will have multiple stamps for author, timestamp, organization, etc. And so, I think we need to figure out how we're gonna deal with those as well, otherwise what we do won't live in the real world.

Terrence O'Malley - Massachusetts General Hospital - Co-Chair

Yeah. And Sheryl, great points. And what we're going to do when we get on, we're going to show you kind of the Google Doc structure that's gonna be rolled out. So, there'll be plenty of opportunity to put your thoughts down on the Google doc sort of in perpetuity. So, then we can all address them and discuss them and wordsmith them, and do all that sort of stuff. So, it'll be an ongoing editing process for the next umpteen sessions. But good points here. They're great. So, you'll bring them up as another question.

<u>Sheryl Turney – Anthem Blue Cross Blue Shield - Member</u>

All right, thank you.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

Great. So, just running through this snapshot – go ahead, Terry.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

I was just gonna say, these slides are really just a quick overview of sort of where we're heading. We don't have to dive into them right this moment. But we will. Go ahead. Sorry.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

Well, no, that's a great point. And I'm actually gonna get through this, because it looks like this group is ready to get into discussion. And a lot of this material is repetitive based on the chart. So, just pulling it up for reference, these are the data elements included in the clinical notes. And again, we will be looking at these eight data elements and addressing any additional that we think should be added.

So, moving on to the next slide. Here's just our snapshot of the pediatric vital signs, which is a new data class underneath of the main category of the vital signs, specifically focused on pediatrics. And here's the data elements that are currently being proposed that we are going to review as a taskforce.

So, moving on to the next slide. We have the patient demographics, which we are actually going to start to look at today. And same charge as the other data elements we're looking at. So, I will go ahead and move on from this one and look at our timeline, I think is next. So, here is our proposed timeline. Today we're going to kick off with a discussion on patient demographics. And I know this is an early discussion, so one of the things that Terry and I were discussing is starting a Google doc. So, today we're hoping to start our conversation on patient demographics, capture some of the dialogues, and then follow up with this group with a Google doc so that everybody can have extra time to add any more information, guiding text, and anything else that's not captured on today's call for a quick review at the beginning of our next call, which will focus on data provenance. And then we will be moving onto clinical notes, and then the pediatric vital signs.

We will have kind of a steep timeline looking at our recommendations to be finalized on May 6th for the full HITAC Committee to review and present on May 13th. One thing I did want to note is that our timeline for our task one is aligned with the other three taskforces going on now. And we're **[inaudible] [00:16:26]** are focused during phase one on our task one. And then after our full HITAC Committee meeting, we will be going on to task two of our charge, which is actually the next slide.

So that you guys know what's coming, phase two of the charge will actually be to provide feedback and a review of the USCDI draft promotion model. So, ONC is working right now on getting us a nice

draft of that, so we're going to be able to really finesse it and provide feedback. We wanted everyone to know that this was coming so that we can once again stay focused on what we have in front of us, which is looking at the proposed data elements. And then this part will be a lot of what we were working on in our last taskforce, on how we get more data elements and data classes into the USCDI and really refining that process. Terry, did you want to add anything here?

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

No, other than should we take a break for questions and comments, and then continue?

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

I think that's a great idea. And I see Steven's hand up.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Yeah. Thank you guys so much. I appreciate the timeline that we're on and the fact that we want to dig into the demographics. But like Sheryl and I think Clem, I have sort of some burning ideas on the top of my head that have come up in my initial review of our charge, that it sort of feels like we should get them out on the table and then come back to them when we do the deeper dive, just so that we sort of don't lose them. And if so, I'm happy to share them. But if not, I can try to save them for later.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Okay. Well, actually, Steven, that's a great idea. And we were gonna share the draft Google doc, but Katie, I'm wondering if it makes more sense for me to bring it up on my computer, and I can edit it as we talk. Can we do that?

Accel

Yes, you can do that.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay.

Steven Lane – Sutter Health – HITAC Committee Member

As you know, Terry, that's worked well for us in some other taskforces, so it's -

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yes, we were bragging on you guys. You and Ken are the masters. I'll try to do something similar. All right, so I'm going to, lord willing, share – all right, wait a second – share my screen. All right. Tell me if you can see it. Not there yet, huh? Got the desktop. That's nice.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

It's spinning.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Lovely. It's my screensaver. But it doesn't want to show the document. All right.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Here it comes. Here we go.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

All right. USCDI data class. Okay.

Christina Caraballo – Audacious Inquiry – Co-Chair

So, Terry, I liked Steven's idea of collecting just general information before we dive in. So, maybe we start a paragraph with bullets at the top.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah, let's go. So, Steven, you're up.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

Okay.

Steven Lane – Sutter Health – HITAC Committee Member

Okay, so just again, these are the things that I've jotted down. Under provenance, I think there are some real key things that we're gonna wanna flesh out, and Sheryl kind of started the list. The idea of multiple timestamps on a piece of data or a document, I think we need to think about how we're gonna manage those. Multiple versions of a piece of data or a document as it may change over time; the idea of reference IDs to connect those multiple versions and keep them together in a bundle. And then Sheryl mentioned digital signatures and blockchain. But this has clearly come up in another taskforce, the idea of needing to manage a piece of data to assure that it's not been tampered with. All of these things have been suggested as components of provenance beyond the few pieces that ONC described in the draft rule. And I think that provenance itself may have its own sort of glide path that expands over time, starting with a small set and moving forward. So, I just think when we get to provenance, those are all ideas that I would toss in there.

And maybe I'll just give you my two other thoughts and then let other people chime in. Under the list of clinical notes, they listed the different notes as data elements, which doesn't make sense to me linguistically. I mean, those are note types. Those of us who have been involved in the whole CCDA patient story project stuff, those are note types. They're not data elements in the way that I think of them. So, I just think we might think about that language. And then the last one on my mind is the pediatric vital signs, I think there's a typo in a lot of the ONC materials. We measure head circumference in little kids, not big kids. We measure them newborns and infants. So, a lot of the ONC documentation says children greater than three years old, but I think it's supposed to be less than three years old. I saw at least one place in ONC documentation where it did say less than three years old, but as somebody who takes care of kids and has for decades, I think they got a typo.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay. Sorry, is that your list?

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Yeah, that was it.

Clem McDonald – National Library of Medicine – HITAC Committee Member

Having said that you'd like to invite other comments, I'd like to weigh in on the provenance just a little. So, there's an activity underway, and I mean, it's out on fire with provenance, and I think there's also one in CCDA, which is more elaborate, that those thinking should at least be thought about in this whole plan. But I think the biggest big thing you need is you need a unique ID for this data element – I mean, that item that's being provenanced, because the biggest problem is you get the same data from many sources. The hospital sends it to the doctor, he sends it to another doctor, but the hospital

also sends it to the doctor. You can't tell which one is the primary original one. And all the things that Steve said I think are also true.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah, and Steve, was it Dave McCallie who did a riff on provenance in the . . .

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Yeah, Dave McCallie from Cerner.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah, could you somehow forward that to us, and we'll plunk that in there too.

Steven Lane – Sutter Health – HITAC Committee Member

I mean, we captured it in our recommendations for the orders and results draft recommendations from the ISP Taskforce. And we took it from Dave and then ran it through the group, so it's in there.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

But it would still be worth kind of refreshing. Is it just an email that could be forwarded?

Steven Lane – Sutter Health – HITAC Committee Member

I mean, I can go dig out Dave's email. I think Dave wrote a whole paper on it. Let me touch base with him, because he and I had a talk about this at HIMSS just a couple weeks ago.

Tina Esposito – Advocate Aurora Health – Member

Terry, this is Tina Esposito. I wanted to not lose something Sheryl had said earlier, and that's really sort of, I mean, a little bit more overarching in some respects. I agree with everything that's been said, by the way. But she said something around the lines of ensuring that what we create sort of continues and stays. And I think we mentioned blockchain, and I will be honest, I am not a blockchain expert. But as you think about provenance, that's sort of something that will absolutely align and ensure that we can use newfound technologies to ensure that we have a very clear understanding of who's touched the record, what's been added, etc. So, I think something along the lines of ensuring that – I don't know if that's a cross-reference of some sort of – whatever some of these emerging technologies are gonna require as data elements, we should do our best, knowing what we know today. And clearly, we don't know everything sort of in what's coming, but we should do our best to ensure that we are establishing and setting ourselves up appropriately for emerging technology to be leveraged and incorporating the data elements that are necessary.

I would also say that that should be true for the patient demographics. I know that the intent is to get there today. But when I look at that, and I think it was also mentioned, it's about identifying patients. And so, when you think about referential identification using old addresses, using a cell phone or a mobile number, where I think guidance from this group would be where we can sort of align ourselves and incorporate those elements for what we know today. We should absolutely do that.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah, good point. Well-taken. And I think that's going to be one of the biggest tasks of this group, and that's to be looking into the future enough to know what's coming, but not so much that it gets in our way of getting something — as Clem would say, the work's right now. Okay, well, that's great. And Sheryl, have we captured your thoughts adequately, or should we . . .

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Very well. You've captured them very well at this point, thank you.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u> Okay. Who else? Anyone else want to weigh in on these sort of big issues that we will circle back to, or use them as our touch points? You can weigh in any time, all right? This is a living document which can live in any different any. So, is this sort of our 1:00 – are we at the point of our 1:00 break, or are we gonna dive into data elements? Or do we have other things to go through?

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

I think we're ready to go ahead into the -

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Demographics?

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

Yeah, the patient demographics.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

We can go ahead and leave your slide up, or your Google doc, if you want.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah. So, you've got a sense of hope I hope this is gonna work. First of all, this sheet is a draft, all right? We can come up with anything we like. But let me walk you through it, and then we can add stuff that's missing or take stuff out that we don't want. But basically, where do we get . . . the notes up above. So, we're doing demographics, right? So, we had a heading for demographics, and there'll be a heading for provenance and PD vital signs, etc. And then what's under this, or what's currently for demographics in the Common Clinical Dataset, which we are replacing, and then ONC, then what we propose in our charge. So, they want to throw in address and phone number, all right?

And then I thought the third category – so, it's what was there, what ONC is proposing, and then what we come up with is sort of the third category. And this is the beginning of the third category, all right? And we can, again, put these in different places. And then I thought it'd be helpful – at least to me, it was helpful to think about if we're doing demographics, then what's the problem that we're really addressing, all right? So, we've got demographics. It's not just demographics. We're doing something with the demographics that has value to us. And then, if that's the case, then why don't we list the things that demographics might intersect with, so we can make sure that what we're proposing in this data class actually meets the use cases that we think have high value? So, let me stop there. That's just the layout. So, any thoughts on layout, or things you'd rather see, or additions?

Steven Lane – Sutter Health – HITAC Committee Member

Yeah. I like it, Terry. I like the idea of starting with the problem. I think that's a good way to think about it. I mean, to me, this really helps me think about – you say what you will refer to as patient identification, in my mind, I think patient matching is kind of the problem. Yeah, I mean, but it's sort of the same thing. You can just say matching/identification. But clearly, we're all well aware of the

challenges of algorithms and deterministic algorithms, and the heuristics that are being done, etc. That seems, to me, critical. And there's actually data out there about what pieces of demographic information do we need to get what degree of a match. I think that's an area where we may want to have some SMEs come in who've actually been part of that mathematical statistical analysis, as opposed to us just kind of intuiting on this.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

I think that's an excellent point. I do want to keep patient matching and patient identification separate. In that recent Pew report that came out, there was patient identification, where I come in and I'm identified as me as I see my provider, and then there's patient matching, where I need to find the record. So, I think they are different.

Clem McDonald – National Library of Medicine – HITAC Committee Member

Clarify. Patient matching is you want to combine records from different places without the same identifier [inaudible] [00:31:27].

Christina Caraballo – Audacious Inquiry – Co-Chair

Yeah. Thank you, Clem. And I see Valerie, did you have a comment?

Valerie Grey – New York eHealth Collaborative - Member

Yeah. I mean, I guess more a couple of questions than a comment. But I do agree with what folks have – sort of how we're organizing the work and the interest in having an SME on patient matching come in. I guess I even had a more basic question, and I'm sort of embarrassed to ask it. But when we sort of say address and phone number, do we mean current address, physical address, mailing address? When we say phone number, are we trying to get at mobile or home, and how does sort of some of those details and how you code street – is it ST? Is it STR? Is it ST? Do those kinds of questions come into play for the work ahead, or am I being too basic?

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

No, Sheryl, I think that's . . . Go ahead, Clem. You were gonna . . .

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Well, I was gonna what you're – I think you're right on.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah. And there's a paper that was just published in the HEMA, and I can put the link up, that goes over that in excruciating detail. So, current address, old address, street, zip, you name it. So, let me get that out to everybody as well, if I can.

Valerie Grey - New York eHealth Collaborative - Member

Okay, great. That's helpful.

Steven Lane – Sutter Health – HITAC Committee Member

Yeah. I mean, when you think about, when you are taken through by those credit agencies or what have you, or when you have to do your self-identification to get a direct address, they've got all your old addresses, right? So, to just say address, it could be a lifetime of addresses with applicable dates, etc. The same with phone numbers – work, home, cell, girlfriend, etc. I mean, it goes on and on.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah. So, HEMA, they did a nice paper. So, I will send the paper – and it's got the appendix – to everybody. But Sheryl, you're absolutely right. And the same thing goes for phone numbers, so. Cell, mobile, work, old, new, whatever. Although isn't it – and correct me if I'm wrong, but isn't the cell phone number one of the more durable pieces of personal data that's coming out?

Valerie Grey - New York eHealth Collaborative - Member

Yeah, that's what I've heard.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah, so.

<u>Valerie Grey – New York eHealth Collaborative - Member</u>

Yeah, that's what I've heard as well. And especially now that it's portable, and it's not like the old, old days, where you had to get a new number every time.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

And I don't see email listed here yet.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Well, so that's interesting.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Could I **[crosstalk] [00:34:18]** some more too? If the idea is that the patient should get all their data, why not have a destination, whatever it'll be – a URL – there's a variety of possibilities. Even a cell phone number – but where it could be sent, where you could send your data, instead of having to go poke around and find it, and then wait to see. If it's not there yet, you go back again.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

How about that? Patient-designated destination.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Yeah.

Steven Lane – Sutter Health – HITAC Committee Member

But I think I mentioned email, and I don't know, you hesitated, Terry. But I think obviously, email [crosstalk] [00:34:54]. One can have multiple. They can change over time. And some of them are gonna be pretty durable. And then there's the whole issue of direct addresses, and patients, individuals, getting their own direct addresses. I think the idea of designated destination to me is like provider's preferred means of communication in our world. So, maybe there can be a designated destination and preferred means of communication, because again, some people are gonna want a text, or an email, or a direct message, or what have you. I think that belongs there too, potentially.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah, okay. So, we're diving in, which is great. But just on the general structure, is that kind of working for people? And if not, let's add something. If so, then we'll keep it up. And then on the problems that we're trying to address, are there more problems –

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

When you say research, Terry, what do you mean? I mean, it seems to me in research, you've got issues of patient matching. But what is research as a problem?

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah, it's sort of the intersection of research and demographics. How much patient detail? Because a lot of research is de-identified, so there is no patient detail. But that's not all research.

Steven Lane – Sutter Health – HITAC Committee Member

So, maybe the problem is – there's a problem related to de-identification and limited datasets, which affect research particularly.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Well, Terry, I'm for research, but I don't think we can just jam that into USCDI's – I don't think it fits, unless you craft it differently. What elements do we want –

Steven Lane – Sutter Health – HITAC Committee Member

Well, we're talking about demographics, right? I mean, that's the key point here. So, what is it about – and I think what you're saying is not about research on demographics or research into patient matching. I think you're talking about how can demographics as a component of the USCDI support research? What do researchers need in the private, public, pharma sectors, etc., from demographics to support their work?

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yes. Thank you, Steve. Well done. All right. So, again, these are just sort of general use cases. Do we have other problems that demographics intersects with that we can think of? Because my thinking is, if we know the problems we're trying to address, then we'll be more complete in what we propose for the demographic data class. We can always —

Tina Esposito – Advocate Aurora Health – Member

Well, just one comment. And I don't want to nitpick here, but give me a little bit here on the pop health analytics. You've got a social media tag.

Terrence O'Malley - Massachusetts General Hospital - Co-Chair

Well, yeah. I was just thinking widely. How are we gonna reach out to patients? Sort of to your point, that the emerging technologies – is your social media tag gonna be a patient identifier, a personal identifier? I don't know.

<u>Tina Esposito – Advocate Aurora Health – Member</u>

Because when I read even the zip code level – so, it depends on how we're defining population health. But I think there is a little bit of overlay with public health reporting in some respects too. If we're thinking populations much more broadly than just patients that have sort of immediately received care, and rather sort of more broadly think – so, it just gets a little tricky. I don't know if those two can be combined or if it makes sense. I'll leave it to the group to sort of comment on that. But I would say that often, what you need for public health reporting may also be beneficial for pop health analytics as well.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

We ought to at least list the possibility, or I don't know if it's actually starting, of a Medicare, a medical record number. I've heard that may be happening.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Mm. I thought they were very clear about no monies can be appropriated for a national identifier.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Well, it's not national. It's just from -

Tina Esposito – Advocate Aurora Health – Member

Oh, it's just [crosstalk] [00:39:52]?

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

I think it's cooking. But I don't know if it's still cooking.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Yeah, I remember hearing that there's a change afoot, that people are gonna be able to start at least researching it.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Okay. Very good. Well, so that might be a data element under the data class of demographics. Under the proposed data elements up here, we can keep adding anything we want. So, Medicare . . . And it may not stay there, but we can put it. Okay. So, the structure's okay. We can approach it this way. So, do we want to tackle a particular problem or problems? How far do we want to take us today? We've got another hour and a quarter. Do we want to blow up any of these?

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u> I think we should go after the provenance a little more.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Well, no, the provenance is next week.

Clem McDonald – National Library of Medicine – HITAC Committee Member

What are we gonna do with the rest of the time?

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

And Terry, this is Lauren. I see that, Valerie, I don't know if you still have your hand up from the previous question. I don't know if she had something else to comment.

<u>Valerie Grey – New York eHealth Collaborative - Member</u>

Oh yeah, no, I'm sorry.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

I'm sorry, I can't see you.

Valerie Grey – New York eHealth Collaborative - Member

That's up from the last time. I'll take it down. Sorry about that.

Lauren Richie - Office of the National Coordinator for Health Information Technology -

Designated Federal Officer

That's okay.

Matt Rahn – ONC – ONC Staff

Hey, this is Matt Ron. Can you hear me? With ONC.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah.

Matt Ron – ONC – ONC Staff

All right, perfect. So, just wanted to know one thing. The head circumference, that was a typo, and we've fixed that, so. Just wanted to make sure you were able to remove that from your list.

Steven Lane – Sutter Health – HITAC Committee Member

I appreciate that. And that typo exists in a lot of places. I'm not –

Matt Rahn – ONC – ONC Staff

Yeah, we –

Steven Lane – Sutter Health – HITAC Committee Member

It's all over.

Matt Rahn - ONC - ONC Staff

Yeah, if you see it – if it exists, we did go through and hopefully fixed it everywhere. But if it still exists, please let us know. Sorry about that.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Well, the power of electronic data to self-perpetuate. There we go. Whether it's right or wrong. So, Clem, to your question on provenance, I guess we can – I don't know. It depends on how we want to organize things. Since we've got time, would it make sense to go ahead and think out some of these broader issues a little bit more?

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Well, again, before we leave demographics, I mean, we've thrown out a lot of ideas, but I mean, shouldn't we – I mean, we're gonna be asked to actually make concrete recommendations. So, I think as we've been throwing these out, we haven't gotten to the level of what would be the recommendation and can we agree on it. Is now the time to do that before we move on to provenance?

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah, I was just thinking provenance in a general way. But no, you're absolutely right. We have to come back and really flesh this out in the detail to which we are comfortable.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

And one thing that's important to remember is this should not be our wish list. We need to actually think about what's feasible to include. The next phase, where we're looking at how we get more data elements into the USCDI, I think will be broader. But right now, it's kind of like what standards exist to support the data elements that we're proposing; what is already in the 2015 edition certification,

whether it's required, or required by providers to use, or at least required for vendors to have. Because I think that's really important.

Steven Lane – Sutter Health – HITAC Committee Member

Yeah, and Christina, I think you're right. I think that we should focus on the data elements within each data class that have already been included in this USCDI version one. And I want to thank Clem for finding and sending the document you found on the web, because it is a really good document. So, I think that we should probably keep our focus on that, and then make a parking lot for each of the data classes to say what else goes there. So, within demographics, we've identified a bunch of stuff that may be needed there in the future. Another one that I don't think we've captured is nicknames. That's really important and wasn't in there. And I see they've got suffix in there, but I think most of us with professions know that suffixes, some people use them for Junior, the third, etc. And other people use them for MD, RN, JD, Esquire. So, I mean, you can't just sort of say suffix without defining which suffix you're talking about.

Race and ethnicity. Of course, so much has been written about that, and I think there are now accepted standards of what is a list of standard races, what is a list of standard ethnicities. Language. I mean, I think each one of these needs to have pointers that go to what is – so you've got the data class, you've got the data element. But then within the data element, you've got to have a list of what's acceptable. And there were some comments earlier about address in terms of how componentized is it? Do you have number, street, city, county, country, or is it just a free text address? I think that's the level of detail we probably want to get into, at least on the data elements that have been identified in the draft version one.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

So, Steven, let me come back to that a little bit on – so, are you proposing sort of a method in which we ultimately – we want to see a list of the components of name, and we want that list to be standardized, and we want that list to live somewhere where it can be referenced, and a list that someone will curate, no doubt? But sort of like the ISA for the data element? Here's the list.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Kind of, yeah. I mean, you said name. I think name is a little tricky. So, first name, or "common" name. I think that's pretty clear. It's interesting, when I filled out the birth certificates for my kids, I had to decide, well, do they get multiple first names, or multiple middle names, or multiple last names? And we decided to give them a bunch of middle names so that their first and last names were simpler. But in some cultures, you've got multiple terms in a first name, or multiple terms in a last name, and we have to think about that, right?

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Some of this stuff, though, has been thought about already and are specified in some of the standards. I don't think that we should be – we don't have the energy, or time, or persistence to be a standards group. So, I think we –

<u>Steven Lane – Sutter Health – HITAC Committee M</u>ember

No, but if those standards exist, we should point to them.

Christina Caraballo – Audacious Inquiry – Co-Chair

Yeah, I would agree.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Well, there are standards for name, and they have those pieces and parts, and they're described better. Now, they may need tweaking. We could make suggestions, but we can't complete them, complete the tweaking. There's last name, middle name, suffix. I think the other issue when you get international is first name and last name aren't the right way to say things. I think it's family name and something like that. There are names that are better generalized, because in Chinese, the first name is the last name. I mean, what we call the family name is the first name. But I mean, we can't boil the ocean on these things. I think we should try to find some things that someone should do and do better.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah.

Clem McDonald - National Library of Medicine - HITAC Committee Member

Let's put them in front of us and then talk about them, what they are now.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Right. So, I don't think we necessarily have to address the stuff that's already in the Common Clinical Dataset. And hopefully, there is a process similar to what you referenced, Steven, where these lists are constantly updated and become the new standard, but that somebody else is doing all that work. I think where we're gonna put our effort will be riffing off address and riffing off phone number, and then adding anything else we think.

Clem McDonald - National Library of Medicine - HITAC Committee Member

Yeah. Well, I think we should sure add something that says which kind.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Which kind of what, Clem? I'm sorry.

Clem McDonald – National Library of Medicine – HITAC Committee Member

Number and maybe even address, you know? Their apartment address, their summer address. I don't know what – I'd have to look and see what other things they're doing with that. But when you register for most things, at least the phone number – there's different kinds, sure. Mobile, and the home, and office.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah. Let's see if what I did was . . .

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

We'd have to say which ones, but I think that they're too vague right now.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay. So, I have to go – all right, so I didn't have it saved where I could grab it immediately, so. But I promise to send that out, because I think it answers a lot of our questions about address. As I said, it goes into excruciating detail. So, I think one of the challenges we're gonna have with a list of potential

addresses, a list of potential anything, is how far down the list do we need to go to get something that's workable?

<u>Sheryl Turney – Anthem Blue Cross Blue Shield - Member</u>

Terry, one comment I guess I would make – maybe it hopefully could be a blanket comment, and I think I sort of heard sentiments similar, so I'm just rehashing what I've heard, but for an address, I would say I think we stay with current address, current home address, whatever. But I would say something along the lines of every effort should be taken to use existing standards that ensure a level of consistency in how this is captured and noted, and if there is no standard, that that should propel basically a group to come together and standardize it. So, and I know that's not perfect, but I think we're not gonna boil the ocean here. And the comments that have been made, there's been a lot of work that's been done to standardize some of these data elements already, so we should just take from that. But I think maybe adding a blanket statement here so that they can get into the depth around name and address, etc., I think would be beneficial.

Steven Lane – Sutter Health – HITAC Committee Member

I love the way you said that. You should put that in the chat comments so they can capture it.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah, better than what I'm trying to write down.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

If I can remember it, I will do that. No problem.

Steven Lane – Sutter Health – HITAC Committee Member

Also, I will add, since we were talking about riffing off address, that in California and now subsequently within the Sequoia project, we started a whole discussion about how to standardize the entry of address for people who are homeless. And there, again, there are not current standards, but that needs to be considered here.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

For refugees or displaced persons. We need to think about those things.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Sure. The pickup fire in California, right? Okay. So, I think on address and phone number, the HEMA will give us some great guidance. So, maybe – and to Sheryl's point, if someone's done the work, let's take it. That's fine with me. So, I guess maybe what we want to do is spend some time on what we might think are potential new ones, and then ultimately, we may prioritize those in terms of what's reasonable now, what's coming and might be useful in the future, maybe just binary grouping. Things like that we might want to put in a fast-track and some that we're gonna put in a slow-track. Does that make sense?

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Yes.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay. All right. So, do biometrics count as a demographic?

Steven Lane – Sutter Health – HITAC Committee Member

I say yes.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah. Okay. So, we need a placeholder, and that's really a future – that's coming, right? Personal ID numbers. Now, some people already have their own direct addresses and certainly their own emails and their own unique identifiers. I don't know how far that's come along, but.

Steven Lane – Sutter Health – HITAC Committee Member

And we haven't gotten into things like driver's license, passport, Social Security numbers, right? There's lots of ID numbers that people have, some of them quite common.

Clem McDonald - National Library of Medicine - HITAC Committee Member

But some of them are prohibited to be released or at least discouraged for use, like Social Security. What are they asking for here? What do they want in terms of ID numbers?

Terrence O'Malley - Massachusetts General Hospital - Co-Chair

Well, if you had a patient – so essentially, Clem, did you bring it up, the patient-designated destination? I can't remember.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Well, I don't think I had it as their ID. It's their personal health record, or their LARD, or whatever they call it. I expect we're gonna have those, because the whole purpose of the Cures Act is to deliver everything to the patient.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah. But in a sense, that would be an ID, no?

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

I don't think it's necessarily the identifier. It may not be connected to the individual. It may simply be a foot locker that isn't necessarily – it's not necessarily an identifier for that individual. I know email address probably is, but –

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

It has to be linked to all their identifiers, I guess. Maybe that's it, so.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Well, I mean, giving an ID won't get it to any particular place that'll save the data.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

If I remember correctly, and David McCallie's work, which was referenced earlier, will confirm this, I want to say that – and I can't recall if it's CommonWell, or whatever the patient matching effort that involved a number of ER companies, I think what they have found was driver's license was a key in helping support better patient matching. The gap obviously that then exists, though, is pediatrics, or anyone not driving. But I think if we take it from the approach that Terry had laid out in terms of what

problem does it solve, I do think the driver's license or the ID, I guess. But the license in particular helps support this notion of better patient matching.

Clem McDonald – National Library of Medicine – HITAC Committee Member

Well, in terms of that, I'd like to put up the last four Social Security, because lots of companies use it, but it's been sort of kept from you and the **[inaudible]** [00:56:45]. We asked for it the last time. They said no. That helps break ties, and it doesn't risk identification of the patient, because that's the part that there's like 100,000 people with each last four pattern.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah? So, if we -

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

In fact, it's just destination. It shouldn't replace or be equivalent to an ID. In the world of direct, I think it's a little bit like an email address, but it's a way to get stuff sent someplace.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

So, it's like – maybe to pull things together, so under the problem of patient matching, we would want to add last four of Social, right? I'm just gonna drop them down over here. Well, for patient matching, it would be this whole ID –

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Keeping all the addresses, I'm told, helps.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

All the addresses. Okay. So, again, we'll get a list of addresses, and we can parse those. Maybe we can do that first next week when everyone's had a chance to look at it. But if we're gonna prioritize things, we need SMEs, SAMP, but that's different. So, if we're gonna add new – so, if we're gonna propose to add new things to this data class . . .

Steven Lane – Sutter Health – HITAC Committee Member

Well, I think a driver's license or publicly issued ID number.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay. So, personal ID number.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Yeah. And you're gonna have to have a type with the numbers. It could be one field, two fields.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

A type. ID number and type.

Clem McDonald – National Library of Medicine – HITAC Committee Member

Right. It's a passport, it's this, it's that. But it gets complicated. And I think there's stuff – this is dealt with in HL-72, is you get multiple license number sources. Different states, etc. I think we could refer to some document that would cover it.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay. Now, I'm all with you. So, again, sort of prioritizing things that we would want to add to this list?

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

I think class four was easy. It might be spellable, unless it's politically rejected.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay. And sort of new elements, maybe it's sort of newer elements short-term and new elements long-term, future. For the short-term elements that we'd want, anything else? Medicare ID, that's future.

Clem McDonald – National Library of Medicine – HITAC Committee Member

I still think – it may not be short-term, but an address for a destination for your record.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah. What sort of address, a real one or a virtual one?

Clem McDonald – National Library of Medicine – HITAC Committee Member

Well, the problem is nothing is totally spread across the world. But the example would be the direct address that some environments have created for this [crosstalk] [01:00:43].

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

All right. So, let's put direct address in. All right?

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Do we have room for email?

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Yeah, email makes sense. I wish -

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

We've got room for everything. We have all the room in the world. This is a continually expanding document.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

But I thought you were looking for the highest priority.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Well, I'm looking for stuff that's sort of short-term and has potential value, and then long-term, which we assume has potential value, but somebody else is gonna figure out. But we're gonna need to put a placeholder in. Yeah, so. Anyway, suffix and nickname, I think we want to add that under name. And these four things I guess are all sort of longer-term up there.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Yeah.

<u>Sheryl Turney – Anthem Blue Cross Blue Shield - Member</u>

I think so. I think that makes sense. The one thing I would add, and I'm gonna throw this out here for comment and thought for the group, but one of the areas that I think has been most important, and it's somewhat kind of an old way of doing this, but a little bit of an a-ha for patient matching, is some level of verification by the patient, meaning that I have this info for you. Is this correct? Is this not correct? Verify. So, I'm just wondering if that idea, and again, it's sort of still forming in my head a little bit – is there an opportunity here to perhaps add a field that identifies this has been verified by

this person, by this patient, whatever it may be? And just, that's an idea. We can leave it. But it just sort of occurred to me as we're thinking about the patient matching scenario.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah. You could almost think of it as two-factor identification. So, bidirectional.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

I think that's an excellent point. And I wonder if that doesn't increase the importance of the preferred method of communication for the patient. Because every time the record is updated, to send an update link acknowledging that the information is correct could be extremely valuable.

<u>Sheryl Turney – Anthem Blue Cross Blue Shield - Member</u>

Yeah, I would agree.

Steven Lane – Sutter Health – HITAC Committee Member

And I think verified itself has dimensions, right? It's verified by whom and when, at the very least, because sometimes a patient is a minor, or is otherwise incapable.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Provenance. Yeah.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

That's true. That's a good point. That may be more of the provenance. But nonetheless, but just the idea, in essence, I think we can think about that and see where it best belongs.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

As someone who's spent a lot of time thinking about adolescent confidentiality, you can have an address that's been verified by the parent and a different one that's been verified by the patient, and they can both be true.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

They can both be true. And one shouldn't [inaudible] [01:03:59] the other, so.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Right.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah. And this gets – anyway. Okay. All right, so for the use case of patient path, patient matching, we've come up with a bunch of things that we have to work into a suggestion list. On the other – so, on public health reporting – again, probably none of these is new compared to what's in patient matching. They just have other data fields. So, zip code is one, but your GPS location is more granular than your zip code. So, beyond what we've done under patient matching, do you think there's anything that needs to be fleshed out in any of these boxes?

<u>Sheryl Turney – Anthem Blue Cross Blue Shield - Member</u>

Not from a demographics perspective. I can't think of anything further.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Thinking about the overlap of demographics and pediatrics, we all think about work addresses as

adults, but kids have school addresses, which can be relevant in all sorts of situations, like disaster response. So, social determinants.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Interesting. So, maybe there's a subset . . . Maybe it's not a work address. It's an alternate address, or something like that. Again, all this might have been worked out by HEMA already and the HIN people, but there's an SME we should have come visit us.

Steven Lane – Sutter Health – HITAC Committee Member

Yeah.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

It seems logical to add pediatrics as a subset under demographics, especially if we're already looking at pediatrics for vital signs.

Steven Lane – Sutter Health – HITAC Committee Member

Oh, right, and then you have the divorced parents and all their addresses.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah. Okay. So, let's do a pediatric subset. Mm. Okay. So, how about if we clean this up a little bit, get it out onto a real Google doc, and let people add comments.

<u>Sheryl Turney – Anthem Blue Cross Blue Shield - Member</u>

Sounds great.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

All right. So, that'll be our homework, to figure out all that. And my homework is to get you the HEMA paper and the appendices, which I'll send out immediately. So, Lauren, we have – we're doing . . .

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Yeah, you're on time. I know we're just a little bit ahead of schedule. But if you want to break for public comment, we can do that now and can cede the rest of the time back to you guys.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

On schedule.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

And we can get started on provenance if we want.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology -</u> Designated Federal Officer

Why don't we do that? Then, Accel, can you bring up the public comment slides? Terry, you may have to – okay, thanks.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Stopped sharing? Yes, I did.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

All right, Operator, if we can just open the line for public comment?

Operator

If you would like to make a public comment, please press *1 on your telephone keypad. A confirmation tone will indicate your line is in the queue. You may press *2 if you would like to remove your comment from the queue. For participants using speaker equipment, it may be necessary to pick up your handset before pressing the * keys.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology -</u> Designated Federal Officer

Are there any taskforce members that didn't announce themselves at the top of the call? I want to make sure I captured everyone. Okay. Then, Operator, do we have anyone in the queue at this time for comments?

Operator

Not at this time.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Okay. Then, Terry and Christina, I'll hand it back to you.

Terrence O'Malley - Massachusetts General Hospital - Co-Chair

Okay. Let me mock up a quick provenance one. So, there's nothing in the current Common Clinical Dataset on provenance. And ONC is proposing – I'm working on this in the background, guys, so bear with me.

Christina Caraballo – Audacious Inquiry – Co-Chair

ONC is proposing author, timestamp and author organization.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay.

Christina Caraballo – Audacious Inquiry – Co-Chair

So, that's our starting block.

Terrence O'Malley - Massachusetts General Hospital - Co-Chair

Author -

Steven Lane – Sutter Health – HITAC Committee Member

I'd suggest we start by fleshing out those three before – and then separately think about additional data –

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

So, it's author, author timestamp, and which one?

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

Author organization.

Clem McDonald - National Library of Medicine - HITAC Committee Member

But these are gonna be useless unless they're bound down better. Your organization – you've got to have a Medicare code or some darn thing for your organization, and timestamp is bound down, but if

someone just types in a name, it doesn't tell you enough about what the test was or where it came from.

Steven Lane – Sutter Health – HITAC Committee Member

Well, let's take them one at a time. You want to start with author?

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Well, you got lab. So, who's the author of a lab test? Is it –?

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Well, exactly. So, the author can be a human being. It can be an institution. You're talking about labs. It can be all the way down to a device within a department within a location within an institution. We have to think about that. With doctors, they may have multiple authors, right? I mean, you may have an attending, and a resident, and a student. You may have a nurse and a doctor.

Clem McDonald - National Library of Medicine - HITAC Committee Member

Well, I'm assuming back to the lab. There's a technologist, and then there's the signing or verifying person, and then there's maybe the overall authority. But I'm looking at this to help me know which test is the same as another one that seems similar, and it's just the same thing. If they don't have it tied down, some of this stuff, they won't be able to figure that out.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

So, Clem, to go back to our – and I'm sorry, I'm having trouble sharing my screen back again. The problem to be addressed is that – can you articulate what you just did?

Clem McDonald – National Library of Medicine – HITAC Committee Member

I think the problem is that in CDA world, you can get three or four same pieces of information from multiple sources, and you can't sort them out, so it just clogs up the record with a bunch of stuff. The pharmacy gives you a prescription. The doctor then copies it into his record and sends it onto the next doctor. The labs are the same thing. So, I think somewhere, we've got to know which is the one starting point of a result, so you can know which ones to pay attention to.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Okay. That's sort of a generalized issue, right? So, the problem is it's difficult to sort out data from multiple sources.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

No, the problem is there's no unique identifier on the data elements, at least in CDA.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah. Well, that's sort of the solution too. But . . .

Clem McDonald – National Library of Medicine – HITAC Committee Member

But maybe it's not feasible. But if you had some identifiers that were defined in a specific way, at least a human could see which ones were the same results.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

I think what we're gonna find is that depending on the data element, the notion of author really

changes. I mean, think about an immunization. Was the author the ordering provider, the administering clinical staff member?

Clem McDonald – National Library of Medicine – HITAC Committee Member

I think in general, we've got too vague of a space here. And the other use is that link it back to the person who made it, because you have questions. But we're running into this stuff, these problems in all of it, though.

Sheryl Turney – Anthem Blue Cross Blue Shield - Member

This is Sheryl. I was thinking about this differently. It sounds, from what I'm hearing, and correct me if I'm wrong, that what you're talking about is basically the collector of the data, and multiple people engage with a patient when they come in for a visit. Multiple people are entering data. I don't know what the capabilities are of all the EHR systems as far as being able to discern how that data's collected, whether it aligns to who's signed in to credit it. But I was looking at this from a sending and receiving standpoint, so that from a data provenance perspective, as a payer, I would want to know that this data is coming from the system at Provider XYZ, versus the lab, versus whatever, not the actual individual who captured the data. Because I think that's a different problem. So, I think we need to first identify what problem are we trying to solve here.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Well, again, I think there's two: to know a pseudonym of sort of uniqueness, think about whether two thing are the same. The second one is to get back to them and ask something about it. Now, it gets complicated because you might know the institution sends you this result, but they send it out to Mayo to get the test results, so. The last handler of it, you want to know? I mean, these are very important questions. I think it's gonna be a tough problem. Do you have an answer, thinking of sender and receiver?

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Well, I think we have to try to solve those problems. I think Sheryl's point is really well taken. If you're a payer, you just want to know that this came from Harvard versus Kaiser. And that's very different than wanting to know whether it was Dr. Smith or Dr. Jones, or whether it was the lab director, or the tech who drew it, or the provider who ordered it, etc.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Exactly. And I do think it's two separate issues. I'm not saying we need one versus the other. I think we need both. Because then I'd focus it down the road, what about when all of these hospital systems and payers and others are learning machine learning? How do I know what has been analyzed by a person and put in versus what's been generated by a machine? I'm gonna want to know that. So, how do we identify it? So, I do just think for simplicity's sake, we need to make categories and talk about it as far as each category goes, rather than it's all one topic.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u> Agreed.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Right. Because there are clearly similarities in provenance. No matter who you are, you're gonna want to know these three things. You are gonna want to know who created it, the author – and we'll, per

Steven's point, flesh that out a bit; when it was created; where it was created. And then there's gonna be some other pieces of information that are gonna be important. And it's almost who's handled it in the meantime, or when was it changed last that are gonna have value, whether you're a payer, or a person, or a writer. So, we may be able to come back to a set of data elements for provenance that meet the use cases of at least those three groups – payer, provider, patient. And who else? I mean, who else are the user groups? It's the same principle. We've got to make sure we're solving –

Steven Lane – Sutter Health – HITAC Committee Member

And we mentioned public health.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Right. [Inaudible] [01:20:26] and public health.

Clem McDonald - National Library of Medicine - HITAC Committee Member

Well, for billing, it's easy. It's gonna be the ones who are sending the bill. In that case, I think we should specify an identifier. And one that should work would be the – I think, but you could maybe help me – is the NPI, the national provider identifier. Doesn't every billing institution have to use that?

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah, I think you're right, Clem. It's certainly used commonly on the orderer, who's ordering it. It may not be who's – but then who's billing for it is also an NPI, I think.

Clem McDonald – National Library of Medicine – HITAC Committee Member

The organizations have NPIs and the individual providers have them, so.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

All right. And sorry to interrupt us, but Lauren, do we need to break? We already broke for public comment. Nothing broke?

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Yup. We didn't have any comments. You've just got about six minutes here.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Okay, good. Let's keep going. And my apologies, folks. I'm taking notes that you can't see, so they're not anywhere as good as when you're talking. We'll hand them out. It's a short list.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

The only thing I would add to the NPI conversation is that whatever identifier needs to be something that – we should acknowledge any other post-acute entity. And I don't know enough what an NPI is – vaguely a hospital, and there's a provider number, etc., that's post-acute as well.

Clem McDonald - National Library of Medicine - HITAC Committee Member

Oh no, taxi drivers have them. Anybody who bills to Medicare has to have it.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

That's perfect. That would be my only thought, is just to kind of make sure that that umbrella is large.

Clem McDonald – National Library of Medicine – HITAC Committee Member

But it may not still cover everybody.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Yeah. So, we'll just call it an identifier across all settings. Question, NPI. Okay. So, as a list of things besides the three that ONC has listed, can you think of other sort of new data elements, new provenance items, that have general utility?

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Well, going back to my old saw, I think people have been proposing a unique identifier. I don't know how you can do it, though, from a whole bunch of independent sources. So, whether it can be conceived or not. But if you had a unique identifier, then you could go to some table and find everything else, maybe.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Right. Well, there are provider registries and patient registries. So, in a sense, if you have a registry number, that's sort of a start.

Clem McDonald – National Library of Medicine – HITAC Committee Member

That'll be many, though, right? Oh, the registries, it's -

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Well, then you end up with registries, so. So, what else do we – for provenance, what stamp on the data would be useful? I mean . . . Would it be valuable to know who last – well, I guess whenever data is modified, does it then get a new ID? Does it keep its old provenance and now take on a new identification that –

Steven Lane – Sutter Health – HITAC Committee Member

We certainly heard that you need to have the original ID to tie all the versions together.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Original ID of data. And then you need a supplemental ID every time it gets altered?

Steven Lane – Sutter Health – HITAC Committee Member

I think we need an expert on that.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Yes, you're right. This is a deep subject.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Use SME. Okay, we'll get one.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Before we finish, I want to throw in a complication on the time. Remember Daylight Savings Time, and the fact that some hours occur twice. That has to be considered.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

It's going away. I don't know how many years from now, but it's phasing out. Right?

Clem McDonald – National Library of Medicine – HITAC Committee Member

And leap minutes and all the rest, too.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Yeah, yeah. Okay. Somebody's had to figure that out. Remember Y2K.

<u>Steven Lane – Sutter Health – HITAC Committee Member</u>

Remember Y2K, right.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Y2K.

Clem McDonald – National Library of Medicine – HITAC Committee Member

The lights all went out. Whether we should also think about a simplest first version, it would accomplish something. I don't think we'll be able to take on everything at once.

<u>Terrence O'Malley – Massachusetts General Hospital – Co-Chair</u>

Absolutely.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

Let's do simple. [Crosstalk] [01:26:10] Now, we've got to figure out who's the one who signs off on stuff for, say, test results and discharge summaries. I guess that's easy. It's gonna be the author. Maybe a definition for author that's well-accepted, who that is in different circumstances.

Terrence O'Malley – Massachusetts General Hospital – Co-Chair

Well, if we think about senders and receivers, so the sender's gonna need to be able to put a stamp on the data that puts their brand on it. This came from me, and I'll stand behind it. The receiver has to know who sent them the stuff. And then –

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u>

If we knew a unique ID for who they called them, these three different things, it wouldn't be too bad. If they had to use an NPI for the institution and an NPI for the provider, and then they had a timestamp. But then there's all the definitions of who gets chosen as those things.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology -</u> Designated Federal Officer

I just want to acknowledge, we are at time. So, I know we've got – we can continue this discussion until – Terry and Christina, if it's okay, we can maybe pick this up at the top of our next call?

Terrence O'Malley - Massachusetts General Hospital - Co-Chair

Sure. So, our homework will be the HEMA article, these two drafts in an editable format where – don't erase anything, but put your comments in next to anything that's there, okay? So, it's provenance. Anything in black, leave. But you can add your own color, your own NPI with your initial, so we'll know where it came from.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Great. Thanks, Terry. And if anyone has issues accessing the document, just shoot us an email, and we'll make sure you have edit capabilities. Christina, were you gonna add something else?

Christina Caraballo – Audacious Inquiry – Co-Chair

Nope, I think we're good.

<u>Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer</u>

Okay. Perfect. Well, thanks, everyone, for your time, and we'll adjourn today.

<u>Christina Caraballo – Audacious Inquiry – Co-Chair</u>

Thanks, everyone. Bye. [Crosstalk] [01:28:34]

[End of Audio]

Duration: 89 minutes