

U.S. Core Data for Interoperability Task Force

Transcript
April 22, 2019
Virtual Meeting

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
Cassandra Hadley	Office of the National Coordinator	HITAC Back up/ Support
Stacy Perchem	Office of the National Coordinator	Staff Lead
Adam Wong	Office of the National Coordinator	Back up/ Support
Johnny Bender	Office of the National Coordinator	SME

Operator

Thank you. All lines are now bridged.

<u>Cassandra Hadley – Office of the National Coordinator for Health Information Technology - HITAC</u> Back up/ Support

Thank you. Good afternoon, everyone. And welcome to the USCDI task force meeting. Today we will be continuing discussions on final recommendations for the rule. And this group will be presenting at the HITAC meeting this coming Thursday. So without further ado, let me jump into roll call really quick, and then I will pass it over to the co-chairs. Christina Caraballo?

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

Here.

<u>Cassandra Hadley – Office of the National Coordinator for Health Information Technology - HITAC</u> <u>Back up/ Support</u>

Terrance O'Malley?

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

Here.

<u>Cassandra Hadley – Office of the National Coordinator for Health Information Technology - HITAC</u> Back up/ Support

Steven Lane?

Steven Lane - Sutter Health - Member

Here.

<u>Cassandra Hadley – Office of the National Coordinator for Health Information Technology - HITAC</u> Back up/ Support

Brett Oliver? Sheryl Turney? Leslie Lenert? Ken Kawamoto? Clem McDonald?

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

Ken is going to be late.

<u>Cassandra Hadley – Office of the National Coordinator for Health Information Technology - HITAC</u> <u>Back up/ Support</u>

I'm sorry, what was that?

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

Ken is going to be late, but he is coming.

<u>Cassandra Hadley – Office of the National Coordinator for Health Information Technology - HITAC</u> Back up/ Support

Great. And I heard Clem and Valorie Grey? Tina Esposito, I don't think she's going to show today. And Steven Ready? Okay, Christina, I'll hand it over to you.

Christina Caraballo – Audacious Inquiry – Co-Chair

Okay, sounds great. So, Johnny, you think – are you going to get our Google Doc pulled up. We are going to go right into the Google Doc, so thanks to everyone for joining. We are in the home stretch of finalizing our recommendations. A link was sent out to everybody late Friday afternoon with the latest version of our draft recommendations, and today we wanted to do a working session and tighten up any content within the recommendations.

I think, Terry and I with our ONC leads have gone through and consolidated all the comments and started getting a structure in place. We do want to go ahead and try to do as much as we can today, and I'll get into the next steps at the end. But as we're going through this document, you will see it laid out with just a brief intro. We added an intro paragraph on overarching kind of recommendations and laying a foundation for the guiding principles that we put in place. Which were to identify data elements from which to build the basic foundation of interoperability and to avoid data elements that seem too granular for V.1 and that are best left for later versions.

So those are our two guiding principles, and as you go through this, each section for the specific data elements has the ONC proposed data elements. And then under the ONC proposed, we have whether we are including them, revising them, or omitting them. And then we have a section for new proposed data elements for V.1. Of the USCDI. So with that, I think we can dive into the first section, but I'll pause and see if you, Terry, wanted to add anything.

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

No. Sounds great.

Christina Caraballo – Audacious Inquiry – Co-Chair

Okay, so I guess let's go right in. I know everybody's read it and is prepared with their comments. So, I think we can – I just gave a brief overview of the intro and our approach. So going into the patient demographics, and I'm sorry, I'm switching between screens here.

Clem McDonald – National Library of Medicine – Member

Could you make the font just a little bigger on the screen? Or give it more space on the screen?

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

That little box with the arrows, at the top. It says share, NC, Johnny's name and all the way to the right, there's a box with four arrows. If you click that it will make it on your screen, bigger.

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

I can do that.

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

Yeah.

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

Well, it's okay now.

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

Okay, good.

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

So, Christina, I was thinking for this overarching recommendations, we actually have three principles, the last sentence probably should be number three.

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

Okay. I'm going to go in and...

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

I can do a change. Somebody's already in there, okay.

Christina Caraballo – Audacious Inquiry – Co-Chair

I think I remember when I was rewriting this, the two concepts kind of were bunched and then the third. But that's fine, I think. Perfect.

Steven Lane – Sutter Health – Member

In that third sentence, you say recognizing the burden, but I think we went beyond recognizing the burden to try to bound the burden that developers face with potential benefits to the community or to patients.

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

We have that twice now. Balance the burden, it's the – okay.

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

In that context, when we get to some of the specific recommendations, I think we have to distinguish how much burden it would be if they have to type them all in the beginning. Or are they just keep – like you have a history of addresses. Just keep the history, then it is not much of a burden.

Christina Caraballo – Audacious Inquiry – Co-Chair

Good point. I think this was kind of – not saying that we were addressing each and every one, but it was kind of like during our discussions, the type of...

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

I think that's fine. I'm not deciding yet. I'm just jumping ahead.

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

Okay, so are we ready to go to the next paragraph, heading into the patient demographics? I see Steven's already typing away.

Clem McDonald – National Library of Medicine – Member

I think we ought to skip to the things we're asking for. Their preliminary discussions aren't as important, are they? Just what are they?

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

Okay, on demographics, feel free to – let's move along. Basically, we have an address and phone number saying we agreed with them. And then we added recommendation...

Clem McDonald – National Library of Medicine – Member

Are those new? Address and phone number?

Christina Caraballo – Audacious Inquiry – Co-Chair

No, address and phone number are the two that ONC had in the draft. So our first section, with address and phone number we were saying what we agreed on. We were just pointing to specific standards and considering an international standard for address. And then for a phone number, we also agreed to the inclusion of mobile as primary and landline as secondary.

Clem McDonald – National Library of Medicine – Member

Okay. Does anyone know what that format is for international address? Because if it collides with Fire, it's going to be moved.

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

We didn't and started to inquire about that question and even got on the phone with Steve to ask. We don't have anything that we can point to, but we are recommending that ONC do a little more research. I think there was at some point some comment, and I don't know all the details. But DOD had recommended the use of international standards at one point. And we don't know what those are or the best ones, but we think that it should be considered and that's why we left this station very vague.

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

Okay.

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

The rumor had it was GPS coordinates.

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

Thank you, Terry.

Clem McDonald – National Library of Medicine – Member

Well, I don't think – that's a whole other thing.

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

Yes, so.

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

So we left it vague.

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

You can translate that – well, U.S. addresses I know are well standardized already and so I worry, and it might sit, that international spec, I just worry that we'll upset a nicely flowing thing. And with U.S. addresses you can get GPSs. Somebody can make it happen.

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

The point is that statement align.

Clem McDonald – National Library of Medicine – Member

Yes, well I just think that – side inter, I don't think it's crucial to what we're saying here. It's just that I worry a little bit about this when the standard U.S. address file has been sent around for 20 years, I mean. I'd be too. And I think it may not collide with international, but I just worry a little bit if we're going to upheave it on this basis of some hope of something newer.

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

Yeah, I think it's just a look into it a recommendation, they don't have to accept it. They should look into it, but they don't have to adopt it.

Christina Caraballo – Audacious Inquiry – Co-Chair

And these links are pointing to – I need to write a sentence so that they become footnotes, but it's basically we had pointed to the U.S. Postal Service as well, to your point.

Clem McDonald – National Library of Medicine – Member

That's probably what they're using now.

Christina Caraballo – Audacious Inquiry – Co-Chair

Yes, those are in the article in HEMA.

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

Okay, so the real meat of this section, thank you, Steven, for your ongoing edit, is probably the important pieces for this section.

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

So are we scrolling down? So, Johnny, I think we can go ahead and scroll down to the new areas, so we have suggestions for additional patient data bulleted, and then underneath the bullets, we have each one. So if you'll just go to the bulleted list first. Yes, perfect.

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

The only – I don't know if this is pointed as much. It's not wrong, but I think exchange seems like back and forth. But there is a need to have a thing where someone leaves a hospital, and they will send them their stuff. That I think is what we should be aiming for. That it should deliver the stuff, they are required to deliver to a site, which could be an email as you said it there. But it could also be a, what do they call that? There is an address now available in – I can't remember. But a personal health record address or whatever. We should maybe put a couple more words in there to hint so that the institution could send them the data that they want to get from their hospital stay.

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

So, Steven, I see this actually goes to Clem's point. Can you just add a preferred destination for electronic communication? First, we were adding a data element which is electronic communication. We had identified email address as a data element that should be captured in addition to address and pulled it aside as it's own. I think the preferred destination is a different thing that we are capturing. This was a recommendation to capture the email.

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

Well, but then you say this could be personal email, direct, or another site. And when you say the site, I presume you mean like a URL address.

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

Well, or a personal PR, or their provider.

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

Or even a gateway. You know, a patient gateway.

Steven Lane – Sutter Health – Member

Right, and I think some of those possibilities would be worth including parenthetically after another site. But some patients are going to have more than one of these. They are going to be more than happy to tell you what their email address is and what their direct address is and what their PR URL is. But one of those should be – it would be optimal, I believe, to be able to a specific one as preferred.

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

Yes, that's a good idea.

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

So maybe we want destinations for electronic communication. Oh, you say, well I'm sorry, you have with the preferred method, my bad. So preferred isn't needed.

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

I should be in suggesting. I just added as a way to capture it as the secondary part if we're adding electronic communication.

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

Would it be too much to say that the patient encouraged, or it should be a specification that the EMR should have a field for this or does this sort of implying it?

Steven Lane – Sutter Health – Member

Well, I think that as soon as we put it into USCDI, that's what we're saying. That the EHRs do need to have a field and be able to note it.

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

Yes, that's what we are saying for all of these things.

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

Well, can we add another parenthetical thing? This is a place where the patient's encounter it. The clinical medical record from that encounter should be delivered. Because that's what the 21st-century care act says. They don't say do it as this level, but they should get it.

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

Yes, is that – don't gateways provide the same or hospitals?

Clem McDonald – National Library of Medicine – Member

Well, I'm for all the options. I'm just trying to give it more immediacy to readers. This would provide a mechanism for delivering to the patient, pushing to the patient, their electronic information. Right now they have to go pole around, they have to go look around and remembering passwords and all that stuff. I'm not saying it very well, but.

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

No, but you're thinking including the term push, so for the destination for pushing information.

Steven Lane - Sutter Health - Member

Well, but the push is functionality, it's not a data element. Right, the address is a data element.

Clem McDonald – National Library of Medicine – Member

Well, I was talking about to give kind of sharpness to this thing. This could be used or sufficient to be able to, that address would be used to push information from the most recent encounter for example. Push the medical record data from the most recent encounter, the current encounter.

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

So, all right. This is probably the URL. Okay, so we chopped that one up pretty good. How does that look?

Steven Lane - Sutter Health - Member

Progress.

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

Progress. Okay.

Clem McDonald – National Library of Medicine – Member

You guys are working hard.

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

I think we have three editors.

Christina Caraballo – Audacious Inquiry – Co-Chair

I don't like that we have electronic communications with the preferred method of communications twice but, we can move.

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

Why don't we just strike the preferred method from it?

Steven Lane - Sutter Health - Member

No, I wouldn't. You might capitalize it because that's another field, but no I wouldn't strike it.

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

Then we ought to add it as another field.

Christina Caraballo – Audacious Inquiry – Co-Chair

Preferred method of communication. So list?

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

Yes.

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

We can do that. This as and. So Terry, did we want to do two separate. So that we have a destination for electronic communications as the first one and then preferred the method of communication as a second bullet because it's different.

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

Yes, and is it a preferred method or is it a preferred site or URL or address or...

Steven Lane – Sutter Health – Member

Destination. It's the preferred destination, really.

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

All right, so just call it preferred destination.

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

Preferred method and destination. So first you say you can capture the destination or multiple, and then there's a preferred destination.

Clem McDonald – National Library of Medicine – Member

Yes, yes. And it has got to be a separate field, where you mark the one that is preferred.

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

Yes. Got it.

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

You know, but I am just nervous, but I don't want to ascertain to the communication which could be, you know, it's time for your appointment. It's not the same as this is how you will get your medical record data. Not that it shouldn't be able to do both, but.

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

Yes, I think it is pretty generic though because those capabilities are going to grow. I know they have over the last couple of years. And now you have appointments, and then you get your lab, to be able to share emails.

Christina Caraballo – Audacious Inquiry – Co-Chair

So should we do this as a plural method, like being able to click multiple? Because I might want it sent to my email, but I also might want it sent to my PHR.

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

Okay. And then you want to make destinations plural too?

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

Yes.

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

Pretty colors.

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

Yes, good stuff.

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

It's funny. When I look at it on the web, it's teal and salmon. When I look at it on Google, it's pink and green. Go figure.

Christina Caraballo – Audacious Inquiry – Co-Chair

I have different colors too. It's confusing me going back and forth. Not really, but.

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

And on mine, blue and pink, so anyway.

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

Okay, so.

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

Next one?

Christina Caraballo – Audacious Inquiry – Co-Chair

Yes. We can go back and break those two up. But let's move through.

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

Do you want me to work on that?

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

Sure. Well, you can read ahead. I mean, I think they are pretty straight forward. But the next one is.

Clem McDonald – National Library of Medicine – Member

Yes, the next bunch are pretty good.

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

So the next one, the consent I think is the only one of the next few that. Let me just make sure this sounds reasonable. All right. So, that's okay? Last digits of Social Security is going to be a big deal. And the optional identifiers, those were any government issued ID, which presumably requires more vetting than other kinds. Again, for patient matching and identity.

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

Are you guys ready to move on to provenance?

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

So we have self-reported gender identity? Is that okay with you?

Clem McDonald – National Library of Medicine – Member

Did we get the last four of Social Security in there?

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

Yes, that's in there.

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

Right. So, Clem, we broke that into Social Security, the last four. And then a set of optional identifiers. It kind of implies that Social Security shouldn't be optional.

Clem McDonald – National Library of Medicine – Member

Yeah, we'll they've stricken Social Security, though.

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

Yeah, the whole thing, but the last four.

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

That should be not so threatening.

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

Well, and if they strike it, they strike it. That's okay, I mean.

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

Yes, I know.

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

EODA will come back or whoever does that.

Clem McDonald – National Library of Medicine – Member

So this provenance stuff, I investigated with one of the experts at Fire, it's different than I thought. They are recommending, but it's not totally iced. There's an ID in the actual content that can be permanent. There is still a bit of wrestling with to which one would be taken as the one. You know if you get something that comes from an instrument to a lab and the lab then validates it. And I think the direction is that it should be doing some final or **[inaudible] [00:26:54]** for release. And then that one – but anyway.

So it is a little different than what I was proposing it's not in the provenance statement. It's in the actual data, the thing. In the observation, it's in the observation. If it's a drug, it's in the drug.

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

So I think that's consistent with what we've got down here which basically proposes adding yet another data element which is the internal ID that that system applies to the data element.

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

But it wouldn't be in provenance. He made a big point. It wouldn't belong there. It's already there.

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

Well, that's fine.

Clem McDonald – National Library of Medicine – Member

Maybe you can fuzz it and say it should be in somehow a related system ID without saying it's in provenance.

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

So you think the unique ID...

Clem McDonald - National Library of Medicine - Member

I didn't understand the model. So what happens is, say like you send a glucose a that's an observation. Provenance tells you where it came from, the things, kind of like what you have. But the ID that persists is in the lab test, and it seems to apply to other objects within Fire. And so I think what you

could just emphasize, there should be a persistent ID for the item of information without saying it has to be within provenance.

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

Got it. Okay. It's really, what we are saying for each data element, is that it has a unique identifier. Some of it is provenance, so authors, organization, and timestamp, is the provenance piece. The rest of the identification comes from the unique identifier applied to the data element which is not provenance. So we can say...

Clem McDonald – National Library of Medicine – Member

And now if you want to get into it, but there's like three unique identifiers. But I don't think it is worth getting into.

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

Our suggestion is whatever they want to pick, but we need a unique identifier. So actually, what we would do is say instead of adding it to provenance – this whole paragraph basically, this area, needs to be – where can I get color. The area that's highlighted in red, we'll kind of get rid of.

Steven Lane – Sutter Health – Member

Wait, you are talking about getting rid of all that red?

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

Well, in a sense. Because the next paragraph, recommending the creation of a unique persistent identifier has the provenance piece, the unique code with the data type. So Clem says the unique code and data type are somewhere else and already being built or made.

Clem McDonald – National Library of Medicine – Member

I think you're right, Terry.

Steven Lane – Sutter Health – Member

Well, we want to make sure we don't lose the notion of being able to reduplicate data items and to tie together multiple versions of the same data item.

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

No, no, I'm for that. But I had a misconception when I was pushing for that. That it's already there in the actual data item but, I don't think it has totally been worked out which one you declare would be the first one, or whether you care. I mean there are still some tangles that I don't know we can solve, but we should be aware of to say, to really nail, okay is it the very first one by the time that you want? But there are cases where you don't want that one, you want the one that's approved. There's a way to say that, but it isn't yet clear in my mind.

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

I think the way that we've got it here if we get rid of the red text sort of summarizes.

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

I think you're right. It's the direction. We're not writing the software code for it.

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

Yes, and they can figure it, again. I mean, we can just point out that we need the identifier for all the reasons that you say. The decluttering. And then the next paragraph after the four bullet points where we said that the identity will persist as the data element is shared. With this, we are just saying that there is an initial data identifier that is created at the birth of the data element and that persists forever. And what gets added to it is anytime somebody changes that data element; we expect another label that says this has been changed by me at this time and here's the original provenance. Does that make sense?

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

I think you're as close as we can get.

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

Okay, all right. That's close enough. And then, I think this is – I think Arian raised this point on the governance requires – this paragraph. This convention requires a governance structure.

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

Yes.

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

Or shared contrite. It just basically says that if we promise if we say the data element is unchanged, we are attesting to the fact that it has remained unchanged and if we changed it, we're telling you that we did.

Steven Lane - Sutter Health - Member

Now, why are we using the term identity instead of an identifier? That's what I am a little confused by.

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

I don't care. Does the identifier make more sense?

Steven Lane – Sutter Health – Member

It does to me. I sort of started modifying it in the paragraph above and then is see we continue this use of the word identity.

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

That's fine. I have no preference.

Clem McDonald – National Library of Medicine – Member

I agree with Steve. But I think we have to remember we are not writing the final technical specification of this stuff. I don't think we can.

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

That is for sure. Yes, and that is fine. And actually, both terms were used at the HITAC. I think Arian again was the one who wanted identifier, or I can't remember. Somebody wanted the opposite.

Steven Lane - Sutter Health - Member

No, I think we all agreed we wanted both. I mean, people identified the need for both.

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

Yes, the subtlety flew by me. I missed it. I'm not sure I understand the difference. Okay. So persistent data element. And then we are on to clinical notes. Okay. I think we can go through clinical notes pretty quickly, keep on going.

Steven Lane – Sutter Health – Member

Well, Terry, were under laboratory results narrative, that first agree with adding this note with use restricted to special reports and narrative for specific laboratory results. How do we define that better or who's going to define that better?

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

I mean, the challenge really is that you get like a complete blood count, sometimes they'll send it as a narrative blob. And we kind of want a way not to say that's valid.

Steven Lane - Sutter Health - Member

Well, let's say that then. I mean, or let's add that. Where the purpose of this restriction is to avoid sending results that might otherwise be sent as discreet field data as a narrative blob.

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

Yes, there you go. Very good. We know what we want to say, we just don't know how to say it.

Clem McDonald – National Library of Medicine – Member

At USCDI, they have a requirement for laboratory tests and values which is structured. I don't have that in front of me, so I don't know if we could tie it for that. I think this is for like special narrative things that the labs put out sometimes like really complicated reports about pathology and the like.

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

Yes. Or unusual lab tests that have a range and they need to have an explanation as to how to interpret it. You know that...

Clem McDonald - National Library of Medicine - Member

It's really risky. It could be a slippery slope to all narrative lab tests.

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

Yes, I think if we just say we don't want discrete elements sent in this note type.

Clem McDonald – National Library of Medicine – Member

Well, could we take more and give an example. For example, a complete blood count should not be sent as a narrative note. It should be sent as a bunch of separate test results.

Steven Lane - Sutter Health - Member

Yes, I think we got it.

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

We might want to throw that in. For example, with CBC results. Yes, I think that makes our intent clearer.

Clem McDonald - National Library of Medicine - Member

Could I just suggest a tiny change, instead of saying blood count result, just leave out the word result? Because it is really up to 20, 30 numbers that you say.

Steven Lane – Sutter Health – Member

How about the result of a complete blood count?

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

Okay, yes. The results of a complete blood count. You might also go a component such as white blood count, hemoglobin, **[inaudible]** [00:39:20] percent. You know, that kind of thing.

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

BLT.

Steven Lane - Sutter Health - Member

We know what it all means.

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

Yes, and no one else will. Excellent.

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

And maybe after hemoglobin, you say, etc. E-T-C.

Steven Lane - Sutter Health - Member

Well, you either get E-G or E-T-C, you don't get both.

Clem McDonald – National Library of Medicine – Member

Well, the problem is, e.g. is closed. It's not just those. So, there are up to 20, 30, results in a blood count, with differential. Well, I don't know. I won't fight over that.

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

That's right. They can. All right. So we go beyond this procedure note we just want to make sure, op note, we still haven't found the answer to that question, but it's kind of trivial. And then we are suggesting we ad all of the rest of these. Seven additional note types. And then on the next page, we do the justification for each. You want to keep going down, Johnny? There we go. Okay.

So what we're saying here is that, and Steve gave the eloquent explanation of the fact that note types other than the CCD in the discharge summary have rarely been employed by developers. And I think the most compelling reason for that is that meaningful use, it allowed them to check the box on meaningful use. Not that they were necessarily the most appropriate note types for the information that was being sent. Okay.

Steven Lane - Sutter Health - Member

Interesting on the – where is it? Did we take out the care plan document? Oh, no there it is. Long term services and support care plan. Yes, this came up with a discussion I was having with the head of Crisp, and apparently, they have some sort of a care plan note that they've instantiated in their HIE that they are shipping around between users. I'm getting more details, and if I find something interesting, I'll share it back with you guys.

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

Yes, actually that is a good question. If I recall in the original HL-7 document types, a care plan was one of the ones we built, and I am not sure why it fell off our list here, good point. Let me look into that right this second.

Clem McDonald - National Library of Medicine - Member

[Inaudible] [00:43:58] but is that different from the long-term services and support care plan?

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

Yes, it is. Yes, they are both care plan notes, but they serve different purposes.

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

But are they both defined already in CDA or someplace?

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

The care plan note is in CDA. And the long-term services support note invalid right now.

Clem McDonald – National Library of Medicine – Member

Okay.

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

As we speak.

Clem McDonald – National Library of Medicine – Member

You must be involved. Are you involved in that?

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

Yes.

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

Good.

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

Yes, it's a very interesting process.

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

I know. Not always fun.

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

Well, two and a half, three years. It was the Taft grants that started it. Let me just get the HL-7 note types.

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

Stepping back, the advanced care planning note, is that the actually advanced directives? Or living will?

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

No, I'm sorry. Advanced care plan note? Yes. Those are the actually advanced directives.

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

So, we don't have to – I mean maybe we should say that, depending on whatever it is in your state or something like that.

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

And it is labeled differently if I remember right. This is Lisa Nelson's. She did this whole thing. It's really labelled as the patient's emergency care plan.

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

Will that is taken to be the formal advanced care. I mean, is this just a note about it or is it the actual patient's document that asserts it.

Steven Lane – Sutter Health – Member

I think that it would be both.

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

Yes, I'm not sure. I mean, you can always append a PDF of the signed post form.

Clem McDonald – National Library of Medicine – Member

What I'm trying to get at is what are we trying to convey that's needed. I'm not sure I get it. Is it something that says yeah, we did it? Or if it's not well defined, we should maybe say a little more.

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

Yes, good point.

Clem McDonald – National Library of Medicine – Member

Or is it in that URL? Does that say it all?

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

No, the URL I think takes you to the wiki, which gives great depth about what's in it. Now let me just see what's in... Oh, man. I pulled up... compliments [inaudible] [00:47:33]. All right, I don't... I thought there was a care plan note. Care plan template, maybe. Let me keep looking. Okay. Well, I tell you what, I if I can find the care plan note, I'll add it.

Steven Lane – Sutter Health – Member

But you are saying you checked that HL-7 link and it wasn't there?

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

Well, I didn't put a link in for the care plan note, just not on our list. But I will go back and make sure it actually exists, and if it does, I'll put it in. I'm sure it exists. I just can't find it. But anyway. Okay. All right. So we are going — and the miscellaneous note was to include anything the note hadn't thought of.

Clem McDonald – National Library of Medicine – Member

So the only thing I worry about that, it might encourage people to use that instead of the specific ones.

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

Yes, yes.

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

And as a predictive example, I would never have thought the price information would have been in that, although I think it's' a great idea.

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

Well, I'm not sure there's – well, I'm sure there probably is a data file for price information.

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

Maybe what we should say, though, is this should only be this should only include those that aren't specified and with more detail. Or somehow a caveat to control it.

Steven Lane – Sutter Health – Member

So, Terry, are you taking out then that link under the long-term services and support care plan note?

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

No, no. That's okay. That one can stay there.

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

That one's okay.

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

Yeah, that one's okay. What I haven't found is there is a CCDA document type called care plan, I just have to see it in writing somewhere. Let me see if that will add care plan. There are all different kinds of care plans.

Steven Lane - Sutter Health - Member

I think for version one; it might be important for us to pick one. And I appreciate that as given your clinical focus with the long-term services and supports is a critical one. But I think we should consider whether it's the most generic and the most appropriate to include in version one.

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

Yes, and that is a good point. It's not generic. It's quite specific, and it is geared for long-term services. What is really nice about it as that it's a consensus document from nine different states who have all agreed on a common vocabulary and note structure even though their systems work very differently from each other.

Steven Lane - Sutter Health - Member

Yes, I thought I'd heard from Lisa that there was a lot of work that had been done on a standardized generic care plan note.

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

I believe it is and if it is, we can call out.

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

Oh, yes, no no. They are definitely in Fire and HL-7. I mean, I know CDA, wherever it is, there definitely is one.

Steven Lane – Sutter Health – Member

Yes, I would propose that we should at least include that. You know, I am not averse to including long term services and support care plan, but at the very least we should include the more generic care plan.

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

I agree with it. I agree.

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

We could say for long term services and supports that we recommend this for the next iteration of USCDI.

Steven Lane – Sutter Health – Member

I think that might make more sense just given where we're heading. Long term care's getting a lot of attention this month, which is good.

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

It's currently invalid and should be added to a future version. Okay. That's fine. So up here is to... Okay, all right. Got it.

Steven Lane - Sutter Health - Member

So should we put in a place holder for the care plan note?

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

Actually, I'm going to switch the order, so we're saying long term services and should go to a future version. So I'll put in the care plan note. I'm sure there is one. So let's put a care plan. So between transfer note and advanced care planning, put care plan.

Steven Lane – Sutter Health – Member

I like it.

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

Okay, so we'll put something in. All right so we'll clean that up. Let's flag that in red just so we don't miss it. Okay. That good for them? So then on the miscellaneous note, that got interrupted. So your point was...

Clem McDonald – National Library of Medicine – Member

We ought to indicate that it's only used for things that cannot be represented in other notes described. That is it shouldn't' be just a downhill slope where they just call everything a miscellaneous note. And then you don't get the structure associated with the other ones. All though I don't know. What do you guys think?

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

Yes. Until standards are developed, right?

Clem McDonald – National Library of Medicine – Member

Yes. You know, I'm not enthusiastic about this quality measure thing. It interacts with so much, and I think we could make things worse. I mean, if they clean up the quality stuff, that would make it easier, but right now, there's nothing that couldn't be quality.

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

Well, you know, to clean it up, I think you got to sweep it into a big pile first.

Clem McDonald – National Library of Medicine – Member

But who is going to do it? Are we going to do it?

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

Well, the question is would it be important to do, and...

Clem McDonald – National Library of Medicine – Member

I'm not sure it's important. I think quality needs more work than just getting the elements together.

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

Well, I was thinking more the inner section between clinical care which is what we're trying to specific data elements for and quality measurements. And so the latest generation of quality measures are basically the electronic quality measures that come directly out of patient care, out of the workflow, use the same vocabulary that was used clinically. As opposed to having to go back into your system and search through numerators and denominators.

Clem McDonald – National Library of Medicine – Member

Well, was your goal to make it simpler? Because I sat through the decisions about this and it was insane. Because what happened was, they started with some fairly simple rules, and then people worried about the exceptions, which ended up being 50 to 200 or 300 data elements that came out of the big healthcare group because they wanted to have the best possible score. But the workload that was required to do that was nuts.

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

And it is nuts. And the more exclusions you have, the less it's a quality measure than it is sort of pole on who is doing what. But anyway.

Christina Caraballo – Audacious Inquiry – Co-Chair

I'm not sure.

Steven Lane - Sutter Health - Member

I still support it. I think there are really important use cases for exchanging quality data between payers, providers, patients, etc. And it thinks the idea of flagging those data elements and kind of being able to group them together would lead to the way this was originally proposed which had some of standardized payload or methodology to move this data. Because we need to move this data, whether we're talking about fire or documents or V.2. This data needs to move today between different stakeholders. And being able to lump it all together I think is important. And I think the way they Terry phrased this where we may already have data items that are used for quality measurement, but there might be new data items that we want to add to USCDI that come in primarily because they're used for quality measurement and that might subsequently have other uses as well. I don't see the harm in this.

I don't see that this creates a lot of added burden. I think it's really kind of just a logical way to keep track of these items and group them together.

Clem McDonald – National Library of Medicine – Member

But most of them are virtual. That is these are not elements that are structured elements when people end up doing it. They do it by manual, half of them, two-thirds of them now. You read the charts.

Steven Lane – Sutter Health – Member

Well, the manual part is just pulling them out. I mean, when was the last time they had their blood pressure checked? What was their last LDL?

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

Those are good ones. But you have all the other things that are just findings that they read through the chart to find to make their measures good. And if you have to put those in a structure, you're really going to kill the practitioner.

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

I think we want to go the opposite way, Clem. I think we want to start with what's in USCDI. See what we've got and can be used.

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

Well, say it that way. We want to simplify quality and make it depend on existing structural data.

Steven Lane - Sutter Health - Member

Yes. Simplify and standardize.

Clem McDonald – National Library of Medicine – Member

The way it is now I think it will be a fishing trip to find even more stuff we got to code.

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

No, this is stuff that's already in USCDI. We're not asking for anything more.

Steven Lane - Sutter Health - Member

And then the next layer is that stuff that's already in the EHR, that isn't in USCDI, and then everyone is coming up with their own way to do it, as you say, picking through the charts manually.

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

Yes, it's really absurd. But...

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

A messy space. I don't think getting in it will make it better.

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

Well, you know, I think the first step – we have to propose the first step. Whether it ever gets beyond that – whether you get the first step, I don't know. But I think this offers a pathway for ONC to begin to get their arms around the whole quality measurement space. And I think it's got to start somewhere.

Clem McDonald – National Library of Medicine – Member

Well, I think you state it a little more strictly. You are looking for things that are discrete elements that are now being transmitted in clinical systems that you can depend on. Instead of saying, let's find everything we can think of. In an open committee, they'll have stuff up the wazoo. Physicians will never get home at night.

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

But the whole point about using specified data elements that are in USCDI, they will have to be in the EHR, and then they can be pulled in the background.

Clem McDonald – National Library of Medicine – Member

Well, then I say existing structured data, USCDI is not that specific even now, you know, it's like categories of stuff. So I think when you say structured elements that are currently like medical records that are part of USCDI, then I would be more supportive going through that, I think.

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

Okay, so we'll add it in and figure it out later. The anonymous kiwi is still there. Structured data elements. That is part of our currently USCDI or that are in the USCDI.

Clem McDonald – National Library of Medicine – Member

Well, I think you want this structured that are in there or that are in electronic record systems too. Because the USCDI has some fuzzy parts.

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

Well, but I'm thinking – yes, I hear what you're saying, but our only lever is USCDI, we can propose new elements for USCDI, but we can't really...

Clem McDonald – National Library of Medicine – Member

I'm not aiming to make data collections greater. I have physicians hating me because I developed electronic records that had in the old days and that people thought it was a good thing and now everybody hates me.

Steven Lane – Sutter Health – Member

But again, Clem, I don't think we're talking about asking physicians to enter any more data here. This is data they're already entering. Sometimes earning it in free text and spending millions of dollars to have somebody read it and fill in a box.

Clem McDonald – National Library of Medicine – Member

But the free text isn't bad. So are you saying they're going to have to code it? That's work.

Steven Lane - Sutter Health - Member

I think by including it in USCDI, we're not specifying who has to code it. Somebody is coding it today because they're using it for quality reporting. That work is happening. What we're saying is when that work happens, we want to collect the data and be able to exchange it in a standardized way, format, methodology. Again we know this stuff is being collected and coded because it's being reported so I don't get why we think that it would create a new burden. This burden already exists. Standardizing it should lower the total burden.

Clem McDonald – National Library of Medicine – Member

It will get passed to the physician. All the other stuff is.

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

Yeah, the whole idea is to let the EHR do this work. Don't let the poor physician have to do it.

Clem McDonald – National Library of Medicine – Member

I know, but that's been the match we've sold for the last ten years, and it's been a burden.

<u>Cassandra Hadley – Office of the National Coordinator for Health Information Technology - HITAC</u> Back up/ Support

That's fifteen after and Terry, we are out of time at this point. So if you want to wrap up with another word or two before we have to sign off.

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

Good work, everybody. We will clean this up and get it out. Again, we will have one more shot at it. So if you would like to add any more comments or edits tonight up until noontime tomorrow.

Steven Lane – Sutter Health – Member

Thank you, guys, so much. Just remember perfect is the enemy of good enough.

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

Yeah, right.

Christina Caraballo – Audacious Inquiry – Co-Chair

Thank you.

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

Okay, great. Thank you all. Thank you.

Christina Caraballo – Audacious Inquiry – Co-Chair

Thanks, everyone, bye.

Steven Lane - Sutter Health - Member

Thanks. Bye, all.