U.S. Core Data for Interoperability Task Force

Transcript March 07, 2018 Virtual Meeting

Midge Kost- Alternative Designated Federal Officer

Hello, everyone. Good afternoon. My name is Midge Kost. Lauren is out on vacation. So, I'll be your alternative designated federal officer for today. Thank you all for your time. I know we have a lot to cover, so let's get started. I will open the meeting by doing roll call. Christina Carabello?

<u>Christina Carabello – Get Real Health – Co-Chair</u> Present.

Midge Kost- Alternative Designated Federal Officer Terry O'Malley? Steven Lane?

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

Midge Kost- Alternative Designated Federal Officer Clem McDonald?

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

Midge Kost- Alternative Designated Federal Officer Brett Oliver?

<u>Brett Oliver – Baptist Health – HITAC Committee Member</u> Here.

Midge Kost- Alternative Designated Federal Officer

U.S. Core Data for Interoperability Task Force, March 7, 2018

I saw Ken is on the line but unable to speak. Valerie Grey?

<u>Valerie Grey – New York eHealth Collaborative – HITAC Committee Member</u> Here.

Midge Kost- Alternative Designated Federal Officer Laura Heermann Langford? Leslie Kelly Hall?

<u>Leslie Kelly Hall – Healthwise – Public Member</u> Here.

Midge Kost- Alternative Designated Federal Officer Nancy Beavin?

<u>Nancy Beavin – Humana – Public Member</u> Here.

Midge Kost- Alternative Designated Federal Officer Kim Nolen?

<u>Kim Nolen – Pfizer – Public Member</u> I'm here, Hello.

Midge Kost- Alternative Designated Federal Officer Rich Elmore?

<u>Rich Elmore – Allscripts – Public Member</u> Here.

Midge Kost- Alternative Designated Federal Officer Eric Heflin? Dan Vreeman?

Dan Vreeman – Regenstrief Institute, Inc. Here.

Midge Kost- Alternative Designated Federal Officer Mike Perretta?

<u>Mike Perretta – Docket – Public Member</u> Here. Midge Kost- Alternative Designated Federal Officer

Rob Havasy?

Rob Havasy – HIMSS – Public Member

Here.

Midge Kost- Alternative Designated Federal Officer

Now, Christina, I will now turn it over to you.

Christina Carabello – Get Real Health – Co-Chair

Okay. Great. Thanks, everyone, for being here. Thanks, again, Rob, for the room. There are a couple of us here at the HIMSS Conference taking a pause for today's meeting. Today, we were going – and here's just an overview of what we're going to do, so we can all have it in mind, as we progress through the slides. First, we want to confirm a consensus on using the two sets of criteria for data class progression. This is the entry, value and technical. We want to review our current sets of criteria, make any additions, discuss how we could select among the criteria to get a smaller set, and review next week's homework. As we think through this, we thought it was valuable to put next week's homework on the slides today. So, we're going to be asking everyone to rank order the proposed criteria and apply your criteria to the data classes you're choosing to see how many steps it takes to go from suggested to the UCDI. Move to the next slide.

Here's a recap of last week's homework. This is a consolidation from reviewing everybody's input. The first was is value the appropriate criterion for entry into the process. All respondents agreed but need more precise definition of what value is. And we need to agree upon a hierarchy of value. For example, what to whom. For the technical, is the technical the appropriate criterion for advancement? All respondents agreed again, but value will continue to drive progress. But technical will be the gate. Some said we may need other categories in the USCDI process. Moving on to the next slide, here we have the value criteria. And we've put this together as a view for everyone to look at what we've collectively identified to date. And then, we want to work to discuss where we're missing anything.

So, under the value criteria, we have three main buckets. The value to the patient, the value to stakeholders, aggregated, and aggregated impact, and demonstrated value. So, four main buckets. And then, you can see the criteria that we have under each. I'll go ahead and go to the technical. And then, we can move back up. So, let's review it all, and then, we can come back. For the technical criteria, here's what we've identified to date as the group. Collectability of data nationwide, standardization of data formats, clear definition of scope of data classes, maturity of data classes, semantic standards, cost of collection collected within standard work groups, standards exist and are in production use, and data class and standards have gone through testing, rollout, adaption. So, let's jump back up to the previous slide and go ahead and open it for discussion for what we have so far.

Clem, go ahead.

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

I don't think these are very good. Quality of life here is patients want to get the data just to know it. I don't think they can convert seeing their x-ray result into quality of life years or convert their glucose into any of that. I don't know how you can make those transitions. And the same with health outcomes. The test results where the note doesn't directly create outcomes. So, I don't know how we use that. The stakeholders make more sense. But it's **[inaudible] [00:06:13]**. And the aggregate impact, again, showing data, there's a lot of indirection before you get health outcomes. So, I don't see how you're going to do that. If you're talking about cost, this is the cost that's the measure of the data. What's the cost of what?

<u> Kim Nolen – Pfizer – Public Member</u>

Hey, Clem, this is Kim. I wonder if that already adjusted **[inaudible]** could have heard that use some of the comment statements for people. But it was like if you're collecting a certain data class, how do you put value to it? How is it going to improve a patient's life? Or what will it to for their condition for improvement? So, I think, at least in the things that I read, that's how it was being used. And then, the cost, the other thing that I've heard is are there different values of collecting different data classes? So, I don't know if I'm reading those the right way, but those are just some different ways that – yeah.

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

Is it cost of collection or the cost of purveying the information in the first place? I don't know what you're talking about. A CAT scan costs a lot to buy. The collection isn't that expensive once you've done it. So, I don't know what the cost figure applies to.

<u> Kim Nolen – Pfizer – Public Member</u>

Yeah. And I'm wondering if there can be different costs like with -

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

And I think the value to the patient, they just want it. They want to know. And I think the value to the patient, they just want it. They want to know. So, I don't know how you – it's not going to be by test or by measure or by report. Maybe it would, but we need a survey from them to say what they would like to know the most. I don't think we'd get an objective measure of what other value, they just want it. They want all of it, a lot of it.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Okay. Steven, did you want to add to that?

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

I really just want to agree with Clem. I think he's absolutely right. I don't think – we're all patients, at heart. But it is, it's very hard to say what the value is. And it's also hard to say what the future use cases are going to be because that value is going to change over time.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Leslie?

Leslie Kelly Hall – Healthwise – Public Member

Thanks. Sorry, I'm at the airport. If it's too noisy, let me know, and I'll stop talking. But I think value to the patient is also does it help them coordinate care, or does it make things more convenient, or bring efficiency to the system or efficiency to their lives? So, some of the importance of the access is not just the clinical but also the efficiencies, the overhead, just making their lives easier. So, I do agree. It is going to be harder to quantify this area, especially in terms of health outcomes or cost of care. For a patient, it's going to be just I want it. And when I need it, it's going to make my life easier.

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

I don't think it helps us to discriminate between the different kinds of things, except that they should get it, and they want it.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

I do think Leslie makes some excellent points.

Leslie Kelly Hall – Healthwise – Public Member

Is everybody in our room on mute?

<u>Christina Carabello – Get Real Health – Co-Chair</u>

I do think Leslie makes some excellent points about needing to – I'm sorry. I don't know what's going on with our volume here. Okay. I'll move on to Michael. Go ahead.

Mike Perretta – Docket – Public Member

Oh, hi, yes. This is Mike Perretta. I don't know how much more value this is going to add, or if it's going to get us more to the specifics we're looking for. But in terms of cost, the way I've interpreted this, at least conceptually, would be cost seems to be the opportunity cost of not collecting that data. At least that's how I've been interpreting that data point. I hope that is in line with what you guys were thinking.

<u>Unnamed</u>

I think we need to define it.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u> Here, here.

nere, nere.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Operator, can we see where we're getting the feedback from?

Operator

It's coming from Christina's line.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Daniel, you're the next person with your hand up.

Dan Vreeman – Regenstrief Institute, Inc.

Hi, thanks. I was just going to hit on the cost one is a tricky one. But I think it's important to think about what Clem was getting at, which is there's a cost to production or collection. And then, that's separately important from the cost of exchanging or persisting or transmitting. And then, in that cost, it's relative to the degree of additional standardization or transformation that might need to take place in order for that information to be exchanged in a sort of interoperable way. And that's all separate from like what does this information in the healthcare system do to the overall expense and cost of care to either payers or to patients who might be contributing and so forth. So, every time we use cost, I think we should be adding some modifiers to say what particular element are we talking about.

Eric Heflin – Sequoia Project – Public Member

For the record, I joined the meeting about 12:30 local time. This is Eric Heflin.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

If we're looking at the criteria that we, the main buckets, are there any that we are missing or not capturing? Or was anybody's feedback from the homework not incorporated into this that we've missed?

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

This is Clem. I, unfortunately, didn't see the mail late Friday and didn't know I had homework. But that's okay.

Unnamed

Hey, Clem, you always have homework.

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

I actually think we have too many criteria, and they're too well defined. And we need to boil down to something that's really practical that we can put it in use. Some of the cost ones, definitely, could be used. In terms of patients, unless we have surveys of what they want the most, maybe we do, we could use that to help adjudicate. And the health outcomes are just too many steps away from just showing data to anybody. And then, we get the question we were talking about individual specific tests or measurements like a blood pressure. Are we talking about clinical measurements in general or lab tests in general? And we can spend forever on all of this, if we don't get it boiled.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Go ahead, Steven.

Steven Lane – Sutter Health – HITAC Committee Member

So, having said that, Clem, I think that, as we're contemplating newly proposed data types, we will likely be able to say whether they're data types that would have a significant impact on

outcomes or costs when and if they can be shared.

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

I'll buy that. Yeah. We've just got to clarify the qualifiers that we're using these names.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Terry, do you have any thing to add? Or should we move on to the technical side?

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

Yeah. Let's move on to the technical side because we want to circle back to both of these as we clarify next week.

Midge Kost- Alternative Designated Federal Officer

Can I just say something? For everyone in the room, can you please make sure the presentation on their computers are on mute, since I think it will help that we don't get so much feedback. Thank you.

[Crosstalk]

<u>Christina Carabello – Get Real Health – Co-Chair</u>

We'll give everybody a chance to read the technical criteria. And, once again, if you see anything that we have not captured from your input from the homework, please bring it up.

<u> Kim Nolen – Pfizer – Public Member</u>

Can I ask a question? This is Kim. So, with the value **[inaudible] [00:16:29]** that are not in the structured format, but they're important from a value **[inaudible]** a technical specification?

<u>Christina Carabello – Get Real Health – Co-Chair</u>

I think we need to discuss that in a little more detail. And we bucketed these separately intentionally, so that we don't weigh one more heavily than the other, and we can see if there is going to be an extreme value. But we've got some technical challenges, and it could help us kind of identify red flags that progress.

<u>Unnamed</u>

And by the same token because something can be done technically with low value -

[Crosstalk]

Christina Carabello – Get Real Health – Co-Chair

Exactly.

Eric Heflin – Sequoia Project – Public Member

So, this is Eric. I have one comment. [Inaudible] specific criteria [inaudible].

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

You're breaking up very badly.

<u>Unnamed</u>

Say that again more loudly.

Eric Heflin – Sequoia Project – Public Member

So, this is Eric Heflin from Sequoia. And we are always testing the criteria including an additional element, which is that the data set in question has also been piloted, I believe, for use **[inaudible]**.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

And I think that is captured in the last bullet. But if that needs to be reworded, we can certainly do that.

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

I actually like his statement better. It's more specific.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Done. Daniel?

Dan Vreeman – Regenstrief Institute, Inc.

Yeah. I wanted to make one comment, which is that I do believe it's useful to separate these two criteria, value and technical aspects. But it is important to recognize that there is different value depending on how – the characteristics of the data relative to the technical criteria. Some information is more valuable to different stakeholders, if it appears in different formats, i.e., it's actually computable, in some way. And so, I'm not sure which side you would sort of make those annotations. But I think you do have to think about them – you have to hold them both in your mind, at the same time.

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

Could we clarify a couple of them, too? We've got data formats, and we've got semantic standards. Some people might think codes work, messages or message like things and APIs. And the other one is the code systems that apply, just so we know what we're talking about.

<u>Unnamed</u>

I just want to make a point. This is not all – there is really important data that is not **[inaudible]**. Part of the progress of the focus are extremely important. **[Inaudible]**. **[Breaking up]**. And I just want to make sure that's covered in the **[inaudible]**.

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

Okay, just clarify. I don't think that notes are excluded. I mean, you're not going to be able to

send notes, if you don't have a little bit of structure. I mean, HL7 v2 sends notes forever, but if you're saying there's no structure, you won't know anything. So, I think there's no exclusion of narrative stuff, but it's got to have some kind of a package to send it to put it anywhere.

<u>Unnamed</u>

Oh, we agree. I totally agree it has to be packaged and identifiable. But I just want to make sure we're not excluding it.

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

Yes, I agree with that.

<u>Eric Heflin – Sequoia Project – Public Member</u> This is Eric, and I agree because [breaking up] [inaudible] [00:20:46].

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

Eric, are you on a cell phone? It sounds like you're under water bubbling.

Christina Carabello – Get Real Health – Co-Chair

Eric is in the room with us, and we are having major challenges. And everybody is muted.

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

I'm glad you're not under water.

[Crosstalk]

[Breaking up and inaudible voices]

[Everybody is cross talking and breaking up. Completely inaudible]

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

This is Terry. Hang on for a second just to see if this works. So, anyone with an open mic, just close it from the **[inaudible]**

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u> It's very hard to make out anything that's being said.

<u>Terry O'Malley – Massachusetts General Hospital – Co-Chair</u> That's what we're trying to fix.

<u>Clem McDonald – National Library of Medicine – HITAC Committee Member</u> Yeah. The closed captioning sort of speaks to it well.

[Breaking up and inaudible voices]

Midge Kost- Alternative Designated Federal Officer

I just want to thank everyone for standing by, as we have technical difficulties. Thank you.

Christina Carabello – Get Real Health – Co-Chair

We might need to call back in, if everyone is having trouble hearing us.

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

Mute that for a second.

Midge Kost- Alternative Designated Federal Officer

I think that's actually the best option, and the rest of us will just hold.

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

Is that the decision, we all should call back in?

Midge Kost- Alternative Designated Federal Officer

No, unless you're in the room. If you're not in the room at HIMSS, you do not need to call back. If you're in the room at HIMSS, I think the best thing is to call back. So, stay on the line, and yeah.

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

Is that the decision, we all should call back in?

Midge Kost- Alternative Designated Federal Officer

No, unless you're in the room. If you're not in the room at HIMSS, you do not need to call back. If you're in the room at HIMSS, I think the best thing is go call back. So, stay on the line, and yeah.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

The HIMSS room is calling back in.

Midge Kost- Alternative Designated Federal Officer

Thank you so much.

<u>Unnamed</u>

Are you folks still on?

<u>Unnamed</u>

Yes, we are.

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

Are we together yet?

Midge Kost- Alternative Designated Federal Officer

Can we have a test from the room to see how the phone is?

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

That was very clear to one outsider.

Midge Kost- Alternative Designated Federal Officer

Hello?

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Hello.

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

<u>Christina Carabello – Get Real Health – Co-Chair</u>

This is Christina. Are we back in the group call?

Midge Kost- Alternative Designated Federal Officer

You are.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Okay. Great. So, I think we've got a problem with the phone in our room, so apologies to everyone. And we are passing around my cell phone now.

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

That was very clear.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Great.

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

I guess one person at a time will be speaking there for sure.

Midge Kost- Alternative Designated Federal Officer

I also want to remind everyone to please use the raise the hand feature as we move forward, especially now, since we're a little behind schedule. We can add time later. But just for a more efficient conversation. Thank you.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

So, I see no hands raised. Go ahead.

Nancy Beavin – Humana – Public Member

I'm sorry. I don't have a computer, so I can't raise my hand.

Christina Carabello – Get Real Health – Co-Chair

It's Nancy.

Nancy Beavin – Humana – Public Member

Thank you. I just have a question, and I know we talked a lot about not wanting to get into real low-level detail and trying to keep us at a high level. But one of the things that is so critical in the industry that we have struggled with for a really long time is legal authenticator on the record. And I'm just wondering if that's important enough to call out, at this level. I know Terry is scrunching his eyes. I just couldn't not say it because it's just critical, at least from our perspective. And I don't want it – I know it's a real nit kind of detail. And that's not the level we're at. But I just want to make sure it doesn't get missed later. So, I don't know if there's a way to do that.

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

I think that will get a very high value just because it's essential to everybody. So, I wouldn't worry about that being bypassed. I think it's going to be No. 1 on the list or No. 1A.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Go ahead, Eric.

Eric Heflin – Sequoia Project – Public Member

One thing, this is Eric, if I could suggest that this is actually back to, I believe, our first meeting. But it was just suggested to me yesterday, and I really strongly agree with it, is to include a value set for the expression of patient consents, so they can be programmatically processed. For example, one standard that does this already is called XACML. And what that would let a patient do is express a rule, such as a "I a patient consent" or this type of sharing of data within this context for this date range for this purpose. And there's a series of related rules. Anyway, I'd like to suggest we consider increasing the value set to include computable consent expressions. Thank you.

<u>Unnamed</u>

So, I think one of the things that the task force will also want to touch on before the middle of March is to **the press** that we're getting proposed data classes into the queue. And so, you've just nominated something from Sequoia. It will automatically get in the queue. But we probably ought to figure out if there's a process.

[Crosstalk]

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

Is there a list of people with their hands up?

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Yes, Clem, you're next.

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

Okay. Well, I think we ought to try to thin this list, so that we can get it done. And I think a couple of thinnings where we have one called standardization of data formats, and we also have collective – there's two things that seem to say similar sub standards exist out of production use. So, why don't we just say that one and drop off the standardization of data formats and drop off semantic standards? And we can subdivide, if we have to. And then, I think we should – collectability nationwide is kind of like the data exists in electronic form now, or something like that. I think we ought to distinguish between and not trying to be prejudicial of stuff that's sitting there electronic. It may not be perfectly standardized but versus stuff that isn't recorded yet. And how we prioritize it is another question.

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

And, Clem, this is Terry. So, I think one of the challenges we're going to have, I agree, we're going to need to send this list, and the question is whether this is sort of a list of high level bullets. And then, under each one of these, we're going to get a sub list of things. Because the ultimate use of this list, in whatever form it ultimately takes, is going to be for ONC to say here's 10 data classes that are being presented to us. Now, what do we do with it, and how do we rank them. And where do we put them in that queue.

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

Yeah, and I get that. But I think this list is a mess. I think it's everybody's ideas thrown on the paper, without any adjudication or clean up. I don't know how they could use it.

Christina Carabello – Get Real Health – Co-Chair

So, very good point. And this is everybody's collective feedback. And now, we need to now look at it, see where – and decide where our big buckets are, where our little ones are, what's missing. Yes, in both of these, is anything big missing? And then, how are we going to bring other little things under that are important? And one of the exercises Terry and I were doing as we were thinking through how this looks is taking data classes that are important to us or individual stakeholders that are very different and start thinking about how they can progress through this, and then, identifying what's missing. Go ahead, Kim.

<u> Kim Nolen – Pfizer – Public Member</u>

Under the 2015 **[inaudible] [00:34:52]**, aren't there certain data classes that are already in that? I mean, that kind of gives you the most **[inaudible]**.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Do you mean the common clinical data sets?

<u> Kim Nolen – Pfizer – Public Member</u>

Yeah.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Yeah.

<u> Kim Nolen – Pfizer – Public Member</u>

So, should that be in here to kind of -

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Well, remember, we're not talking about the specific data sets. We're talking about a process to get data sets from being looked at, so just emerging to candidate to actually being in the USCDI. So, those are the ones that have already been identified as these will, most likely, be in the first version so the USCDI. And how do we create the framework and process for the next one that will be included? Ken, I see your hand up.

Ken Kawamoto – University of Utah Health – HITAC Committee Member

Yeah. I would suggest maybe looking at all of these. It seems like you can boil it down to two concepts. The cost of sharing without very much structure, and the cost of sharing with type semantics. Anyway, that's just a suggestion of maybe – everything else is sort of a sub bullet of those ideas.

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

I like it. I like simple.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Steven?

Steven Lane – Sutter Health – HITAC Committee Member

I was going to, actually, challenge the fact that we had cost on the technical list at all. The cost is clearly related to the value. But I don't see it as a technical criterion.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

I think that's a good point, and maybe it appears in both. But I would challenge that and say, with technical, it's like how much is it going to cost to developers.

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

It's hard to deliver it.

Steven Lane – Sutter Health – HITAC Committee Member

So, that's not cost of collection per se.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Oh, yeah.

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

That's a very good point. I think Clem was right. There are different costs. And the cost of collection is one. And that probably falls in the value piece. If it's really high value, and it's really hard to get, then, you're going to have to think about what it's going to take to get it. And then, there's another set of costs as the technical hurdles are overcome by the data class moving through this process. And it's going to be sort of what's the incremental cost to finally bring this into the data set. And that's going to be production and standardization and testing and recoding and all of the associated costs of making a data class interoperable storage. The whole genome as a data class, as a cost. That's just how I'm thinking about it. I don't know if that makes sense.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Yeah. I'm going to move right along because we've got some hands raised, and we're getting low on time. So, Ken, go ahead.

Ken Kawamoto – University of Utah Health – HITAC Committee Member

Yeah. So, I think we're talking axes. So, there's an axis of is this something, in terms of clinician burden, user burden, and then, the technical burden of sharing. I do want to keep bringing in this notion of is it structured, or is it not structured. So, for example, it may be relatively cheap to say we're just going to share every free text data note that's in the system. And all you have to do is you have to provide us a label whatever you happen to label it. Be it SOAP note, clinic note, whatever, without having to put it into a standard structure. And that might make that, hey, this is a really high value, low cost thing we should share. And then, but other things like we're going to start really putting a lot more semantic tags on every single note type of the hundreds or thousands of note types that exist. Do you have to map it to these structured codes?

That changes the equation a little bit. So, I just want to make sure we don't lose this notion of structured versus unstructured.

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

And that's a great point. And there's lots of data that is unstructured and very high value. And I guess one of the questions, for us as a task force, is, at the end, we want ONC to move high value data classes forward as quickly as possible, given whatever technical barrier. If it's a high value like clinic notes, and easy to get if it's unstructured, then, that might move very quickly through the process of getting this particular data class into the final data. So, one thing, put that in the parking lot of the question we'll come back to is sort of fast and cheap. Is that a good thing? And to the exclusion of building things that may take more time and effort but also are high value. And we don't want to lessen the net value of that sort of category.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Rob?

Rob Havasy – HIMSS – Public Member

Actually, Terry covered most of what I was going to ask. The only point I want to make and clarify is that when we look at this whole list of technical criteria, we're thinking of implementing

them at different stages, right? So, cost may be evaluated differently in emerging versus things that are going into the CDI versus things that are just suggested. And as I think I mentioned a word in some of my homework, my intent was to really think of an incremental cost and additional burden to the existing exchange system. And that we should try, on balance, to minimize that, if possible. So, if we had a competition between several elements, and we couldn't get them all in there, we might take the one that was less burdensome to the existing exchange providers first and give them some more time to incur the additional costs of a totally new data class.

And that's where I think that's fine. But if something is already in exchanged use, then, there's almost no additional cost. And that would be given preference. I think that's where my mind was.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Thank you. Eric?

Eric Heflin – Sequoia Project – Public Member

Very briefly, on technical criteria, I'd like to suggest we also include that the item in question is necessary and sufficient to satisfy the requirements of an approved use case.

Unnamed [Inaudible] [00:41:37].

Christina Carabello – Get Real Health – Co-Chair

I think that will probably tie back into the value, as well. That's an excellent point. Clem?

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

Yeah. A lot of committees that are like this is you actually edit what's on the screen from the comments. I fear that we're going to have all of this discussion and that we're going to be back to ground zero. Is there any way to change this process? I don't know what's going to happen. I don't know that anything is progressing.

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

Yeah, Clem, that's a great comment. We'll look into that. I think, to a certain extent, we're bound - I don't know what we're bound by, whether we can edit as we go or not. That would be great, if we could. I'm not sure if we can.

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

I mean, this is not a precious list. It's just what everybody said piled together. And if they were talking, well, that's the same. I meant that we could agree to make it clearer or simpler. They overlap.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

So, that's why we want feedback on where are the overlaps, so that we can get a very concise

list.

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

That's what we're trying to do.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

What changes would you suggest making?

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

I'd go with Ken's first suggestion. And then, we'd tweak it some.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Nancy, go ahead.

Nancy Beavin – Humana – Public Member

This is Nancy Beavin. I would suggest, on this list, that we make a change to cost of collection to say cost of implementation of that, so the cost of collection might be the description above. And the cost of implementation might be down here. And then, I would recommend that we take all of the four or five lines that are about standards, and I think we could take all of those set lines that have standards as part of their description here and come up with a single line that addresses data standards. So, that would get us a more consolidated list.

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

Here, here.

Christina Carabello – Get Real Health – Co-Chair

Laura?

Laura Heermann Langford – Indiana University – Public Member

Along those lines, I think the maturity of data class is duplicating what the data class standards have gone through testing roll out adoption.

Christina Carabello – Get Real Health – Co-Chair

Daniel?

Dan Vreeman – Regenstrief Institute, Inc.

Yes. I'm not sure exactly where it fits. And it might be in that maturity of data class thing. But there is a concept I want to build on where Ken was going, which is the idea of that in practice, or in the wild, in particularly data class maybe sort of already kind of standardized in terms of how people are collecting or recording that, on one end of the spectrum. But on the other, you might be in these very emerging or amorphous domains where, in practice, people are doing all sorts of and in different kinds of ways. I think like social determinants itself, clearly, high, high value. But there are many, many, many different ways or **[inaudible] [00:44:57]**. And even though there might be particular standards that could be used, we sort of survey or test out in different areas of how it's being done, there's still lots and lots of variability.

And that's a different dimension, I think, than whether there is a good technical standard that could fit the bill. Just people aren't doing it probably because they're doing it a different way. And I think that has to do with maturity. But I'm not 100 percent sure.

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

Yeah, this is Terry. That's a great point. And it makes me wonder whether we need to have standards – whether standards kind of go towards the end of the list of criteria, and whether you can collect it and move it. And you've already established its value. Ideally, they'd all be standards based. But if it's not standards based, really, who cares, at this point? As they mature, and as they get values, the standards, I think, will probably rise up to meet them. The progress note will be structured at some point. It's not now, and it won't be for a long time.

Christina Carabello – Get Real Health – Co-Chair

Kim?

Kim Nolen – Pfizer – Public Member

I was just trying to summarize what Dan said. I wonder if like consistency and use of documentation are **[inaudible] [00:46:19]**.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Clem?

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

Well, I just want to clarify with Terry. You got to realize, yes, you can take a text note that doesn't have paragraphing or structure. But if you don't have a label on it and a patient's name and other stuff in a standard message, you can't get it, or API. It's just like fuzz balls under the bed. You can't put it anywhere. So, I want to distinguish the business bout having fully structured pay load versus having structure that can deliver a pay load like the bar codes and box cars. We don't have to know everything that's inside of it, but it won't get to the right place, if you don't have something that identifies the package.

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

Clem, isn't that assumed? The pay load doesn't have to be structured, but doesn't the transport standard sort of be assumed? Are you going to put it –

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

Yeah. But I don't know if that's what you were saying. I just wanted to be sure that you're not saying it doesn't matter anything. Somehow, we'll write something on a piece of paper and send it off. Yeah, okay. We're in agreement then. It's not literally a transport standard. That's at a different level of the stack. We need something a little higher up. Health Level 7 or the APIs.

Christina Carabello – Get Real Health – Co-Chair

We have about four minutes left. So, Laura, I'm going to go ahead and pass it on to you.

Laura Heermann Langford – Indiana University – Public Member

I just want to emphasize what Clem is saying. We have to have some level of standards in this, or you won't know what the data is. It's going to be too hard to manage it. We have to come to some level. It doesn't mean that everything has to be standardized to the nth degree. But we have to say that there's at least some bit of standards, or it's not helpful to move it at all.

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

Agreed.

Christina Carabello – Get Real Health – Co-Chair

Yes, go ahead.

Eric Heflin – Sequoia Project – Public Member

This is Eric. The other criteria I would add, I think we probably just want to get some more detailed discussions is let's ensure that we recommend to ONC that these standards be curated. We got bitten by this before with HITSP/C32 where we had a lot of **orphan** standards, and they were being used and are still being used today, with no venue for remediation or maturation or correction to those. So, again, I think we'll probably cover that later, but I just wanted to mention it as important sub criteria. Thank you.

Midge Kost- Alternative Designated Federal Officer

Terry and Christina, do you want to go over this week's homework assignment?

<u>Christina Carabello – Get Real Health – Co-Chair</u>

We can bring it to that. Does anybody have any -1 think the homework will be quick to cover. Does anyone else have anymore comments before we move on to the homework?

Clem McDonald – National Library of Medicine – HITAC Committee Member

Well, let's get a better starting set, with the input that we've given today. If it's just the same, we'll go over the same hashing again.

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

It will be different.

[Crosstalk]

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Okay. We can move on to the next slide. So, we will be sending homework out later this week. Just a reminder to everyone, we're going to have you rank order of the prioritization criteria,

apply your criteria to a data class, which we kind of mentioned earlier to see how this would work, and be prepared to discuss additions, priorities, and steps in the USCDI process.

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

Would it be possible to have the subcommittee make sure we have something we can actually order against?

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Yeah. I think we can definitely discuss any subcommittees with ONC team and see if **[inaudible]**. If you have a specific subcommittee that you have in mind that would be helpful, please feel free to shoot us an email or suggest mail.

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

One addition that we forgot to put on, we were thinking of maybe trying to extend the session by half an hour, make it an hour and a half. Our last 100-yard sprint.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Yeah. Okay. Wonderful. I think we can go ahead and open it up to public comment now.

Midge Kost- Alternative Designated Federal Officer

Operator, can you please open the line for public comment? As a reminder, we ask everyone to keep their comments to two minutes or less.

Operator

Yes, thank you. If you would like to make a public comment, please press Star 1 on your telephone keypad, and a confirmation tone will indicate that your line is in the question queue. You may press Star 2, if you'd like to remove your comment from the queue. For **[inaudible] [00:51:41]** equipment, it may be necessary to pick up your handset before pressing the star keys to place your comment.

Midge Kost- Alternative Designated Federal Officer

Operator, do we have any comments?

Operator

No comments, at this time.

Midge Kost- Alternative Designated Federal Officer

If there are no comments, I will turn it back to Terry and Christina.

<u>Christina Carabello – Get Real Health – Co-Chair</u>

Okay. I think we're ready to go ahead and close the meeting. And we will speak to everyone next week. Thank you all for joining. Terry, anything else?

<u>Terry O'Malley – Massachusetts General Hospital – Co-Chair</u> Thank you.

<u>Christina Carabello – Get Real Health – Co-Chair</u> Thank you. The meeting is adjourned.

[End of Audio]

Duration: 53 minutes