

**Meaningful Use Workgroup  
Subgroup #2 – Engage Patients and Families  
Draft Transcript  
May 15, 2012**

**Roll Call**

**Operator**

All lines are now bridged.

**MacKenzie Robertson – Office of the National Coordinator**

Thank you. Good afternoon everyone, this is MacKenzie Robertson in the Office of the National Coordinator. This is a meeting of the HIT Policy Committee's Meaningful Use Workgroup, subgroup #2, Engage Patients and Families in their care. This is a public call and there will be time for public comment at the end. The call is also being transcribed, so please make sure you identify yourself before speaking. I will quickly go through roll. Christine Bechtel?

**Christine Bechtel – National Partnership for Women & Families – Vice President**

I'm here.

**MacKenzie Robertson – Office of the National Coordinator**

Thanks Christine. Charlene Underwood?

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

I'm here.

**MacKenzie Robertson – Office of the National Coordinator**

Leslie Kelly Hall?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Here.

**MacKenzie Robertson – Office of the National Coordinator**

Neil Calman? Paul Tang? Eva Powell, you're on the phone as well?

**Eva Powell – National Partnership**

Yes.

**MacKenzie Robertson – Office of the National Coordinator**

Okay. And is there any ONC staff on the phone that can also identify themselves?

**Josh Seidman – Office of the National Coordinator**

Josh Seidman.

**MacKenzie Robertson – Office of the National Coordinator**

Thank, you Josh.

**Michelle Nelson- Office of the National Coordinator**

Michelle Nelson, ONC.

**MacKenzie Robertson – Office of the National Coordinator**

Thanks Michelle. Okay Christine, I'll turn it over to you.

## **Christine Bechtel – National Partnership for Women & Families – Vice President**

Great. Thanks and welcome back everybody, to our subgroup on engaging patients and families. I thought I would start by sort of catching folks up on the work that has occurred offline between the last call and this, and share with you my thoughts for how we would proceed today in this call and get your feedback on whether or not that sounds like a plan. So, our agenda really is to keep plugging away at the draft concepts for objectives for Stage 3. We're not going to deal with measures and thresholds and all of that yet, but we do need to get to a set of concepts that we can really start to hone in on. So, you had a couple of documents that went out to you; one is a revised conceptual framework, and that's in your email and it's called conceptual framework draft MU subgroup. It should also have been posted on the website, and that is an updated document that I'll talk about in a second. And then the third is a document from the Patient Engagement Power Team that Leslie Kelly Hall worked on from the Standards Committee, that blends some policy and standards issues and contains overarching themes and principles around patient and family engagement, and that's a second iteration of a document that you received prior to the last call, with some additional detail.

So, what I thought we would do is to really focus in on the document, the conceptual framework draft, and start to get comfortable with that, because we've made some significant changes to it based on the work from the Standards Committee's Power Team. I get Power Team, Tiger Team subgroup workgroup confused, but I think everybody does. And also, want to refer to the use cases that we sent out prior to the last call that came from the VPC as a double check to make sure that we have the core concepts captured in the framework document and then start to really go through the framework document together and have some discussions about . . . there are a number of key issues in there that I think we need to talk about. So, if that sounds like a plan for the next hour that would be my suggestion. Anybody have comments or thoughts about how they would like to proceed? Okay.

So, if you look at the document, the draft conceptual framework, you will see that the first part has remained the same, the summary of patient-centered care, consumer definition, which is the four domains by which we have organized the potential concepts or functionalities for Stage 3. But, the second section is new, and that's the set of key principles. And so, what we did was to take the document from the Power Team from the Standards Committee, and go through it and really extract the core principles that are sort of policy related, because I think that they give a very strong sense of much more specific context to why things are showing up in the conceptual framework table that is immediately following the principles. So hopefully you guys have had a chance to look at those principles. I'll ask you guys for thoughts and comments on those in a second, and I'll try to go through them pretty quickly. And then what you've got below that is the revised table, and that is again revised based on a little bit of feedback from the last call, also based on the use cases from the VPC and then, most significantly, revised from the Power Teams grid document that again you also have in your email and posted online. And so we were able to, thanks to Leslie Kelly Hall, to put together a more substantive list of concepts that we might focus on, and so I will come to those in a second.

So, turning to the principles that are on, they start on page 1. These are essentially much more contextual to Health IT and to what patients and families, family caregivers might need and how they tend to view both healthcare and patient-centeredness, but also in terms of technology and access to information and the functions of technology. So, the first couple talk about consumers as a credible source of information, who can generate very meaningful and material data that is relevant to their care. They talk about being really whole-person oriented, which is to say that healthcare should fit into our lives and not trying to fit our lives into healthcare, which is a little bit the reverse of how we tend to do it today, and what that means. A principle on support and empowerment and the tools that are needed to receive effective care, as well as to prepare for that. There's a principle on information exchange, "I'm a health data exchange of one and so my access to my own health information needs to be timely, it needs to be secure and private." There's also a principle about "I am a necessary and important safety check point." So that means, being able to correct errors in the data, but also knowing about when recalls or alerts are known. And then, the next couple are really around preferences and consumer viewpoints on how they define their care team and their care experience. And then finally, the remaining three, which are on page 2, are around how you know that you're getting the services that you need and not the ones that you don't, as well as what opportunities there are in research, like clinical trials; and then, of course, the

principle on how patients can contribute to the success of clinical quality measurements. And finally, a principle about sort of self-definition, which is “I am the sole source of information with respect to my race, ethnicity, language, etcetera, and that my preferences are mine to define.”

So, I thought that was a great body of work from the Standards Committee group that Leslie led, and we’ve incorporated them here. Any comments or thoughts on these principles?

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Yeah, Christine and Leslie, the one that seems to be missing, and it might be woven in, I’m sure you had this discussion, was around accountability. So, for instance, I own my health, I’m accountable for my health, therefore, I have responsibilities to make sure that I can be as healthy as possible and unless we . . . and I have responsibility to take my medication, I have responsibility to be educated on what needs to happen, I have . . . I don’t see that empowerment there. Certainly we need tools to do it . . . the principles strike me more as being done to rather than being accountable, if you will.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

I think that’s great, I mean, “I own my own health and wellness and really define it myself,” right, because my quality of life might be more important than anything else. So, that’s a good catch.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay, so I think what I’ll do is maybe suggest a slight adaptation that is somewhere between what Charlene is looking for and what Leslie’s suggesting; so something that says “I want to be as healthy as possible, I own my own health and wellness and I define what that means.”

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

But, Christine, “I’m accountable.”

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah, I have a little bit of hesitation about that Charlene, only because I think it’s part of why we’ve put in here the principles around the partnership with the care team and support and empowerment, because what we’ve experienced is that the accountability, responsibility piece number one doesn’t really resonate with consumers, because what they say is “of course I’m accountable, I live with my health every day, there is no more accountability than that.” And then, when we actually . . . we’ve gone out and trained, thousands actually, of patients around patient empowerment and when they got to the point of being really activated and feeling very responsible for their health, and they went to the practice and said, “okay, I’m taking charge of my health now, and here’s what that means for me,” it wasn’t received very well and that was almost a universal experience across all these trainings that we did, and so we tend to focus a little bit more on creating a healthcare system that welcomes that, and giving consumers the tools to do that, but letting them, as Leslie says, define what that means for them.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

You know, I’m going to push back a little more. Again, part of that accountability is, when you’re going in for having a test done or that kind of thing, there are certain cases when you can bring that information with you, there’s cases . . . you’re going to challenge, does this really . . . okay, why do I need to have anesthesia if I’m just going to have a lesion taken off my face, and just . . . because they’re going to make . . . we have to be pushing back on those kind of questions to drive down the cost of care, because . . .

**Christine Bechtel – National Partnership for Women & Families – Vice President**

That I agree with, absolutely. I think it’s the language of accountability and responsibility that mean different things to different people...

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Yeah, so I’m just saying...

**Christine Bechtel – National Partnership for Women & Families – Vice President**

...how do we capture that.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Yes, okay.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

So, just because I am accountable for my care, I own my wellness and my health and that's under my definition. If I am a patient who believes in a holistic approach and I've been told I have cancer, I will take very different modes of care, but I am held accountable because I've defined the care that I want from me. So, I think accountable gets to "you should," so we're should-ing on people instead of saying, I own my health and wellness and I define what that means. I know I'm accountable and that accountability is mine, but I get to define it and I think that's a really important way to . . . also we've been using the term or testing the term accountable patienthood, nobody likes it. They feel it's again, you're telling me what to do instead of me telling you how I want to be held . . . how I want my health and wellness to appear. So –

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

I want them to be mindful of the care and the cost is all I'm saying. That's . . .

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Uh huh.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

That's, you know, you get where I'm going...

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah, okay...

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

But, I hear you so ...but it's just, and I'm... you can give me bad ratings too, because sometimes I don't take that full course of medication, and as we get educated, we're better, right? But, those are... so somehow that has to be built in to our focus.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay. Let me do some work with the language, because I completely get the concept, so let me do some work finessing the language and in the next iteration we send out, we can add that. Sound good Charlene?

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Yup, yup.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Great, other thoughts about anything that's missing or anything the folks don't like here?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Christine, just to . . . it's Leslie again, one thing that we had talked about is the other principles from the Standards Committee that are more systems oriented, we will continue to work on that on the standards side, which was EHR actions how the corresponding dpatient-facing action and the idea that patient-facing systems don't have to be held or encumbered by legacy. So, we'll take that on in the other group.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

I think that's great, and to have a document similar to this, which you really already do, that is really focused on standards and some principles around that would be really helpful.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Okay.

**Eva Powell – National Partnership**

Hey Christine, this is Eva. I think in that second bullet, “I’m more than my illness, health care should fit into my life, not the other way around,” that might be a good place to talk a little more specifically about community support and the healthcare systems role in making linkages there. I don’t know think it needs to be really long, but, just to...

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah, that’s great, that’s a good suggestion. So, I just added “better access linkages to community supports, administrative conveniences and improved communication.” Does that cover it?

**Eva Powell – National Partnership**

Yes, yes.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Great call. Any other thoughts? Okay. All right. So let’s roll into the table. I think what we should do is sort of take a look what’s in the table and then, either this call or the next, depending on how our time goes, we’ll go back to the use cases that we used and double check them. I had about . . . a couple of remaining questions. I did take the liberty of going through the use cases and making sure that the functionalities and concepts contained in those three are reflected here, and for the most part, they are, but there about one or two questions that I had. But let’s go ahead and dive right into this, and what I’m going to do is convert this table to landscape so that I can expand that notes column and I’ll go ahead and kind of take some active notes, I’m sure Michelle will as well, so that we can go through and flag any questions we have. There may be some hand-off that we want to make to other workgroups or Committees, or whatever may be the case. So, I’ll start to flag that along with Michelle, or start to track that rather.

So, in the first domain of whole person care, what we tried to do here was really focus not on everything that’s in Stage 2 necessarily, but trying to think about new things or things that are maybe there’s a basis in Stage 2 or Stage 1, but that needs some adaptation. So, the first one is a good example of that, and that’s patient specific education materials and reminders, which are both in Stage 1 and proposed for Stage 2. But, the nuance or the caveat here is that they would be delivered in the top 10 primary languages, which was something that we’ve talked about in the Policy Committee and in the full Meaningful Use Workgroup previously, but Leslie suggested, and I think it makes sense, that you also narrow the sort of pool here, by calling for the top 10 primary languages, only for the top 100 diagnoses, treatments and tests, because otherwise this could be anything under the sun. So, any thoughts on this one? Do we know what the top diagnoses, treatments and tests are would be my first question or...

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

We would know based upon... the CMS data would be able to tell us what those would be, based on volume, and they would... we would be able to find out the top languages, but, I think there is also discussion, it would be nice to know how the languages are determined, because they can be very different by region, so, it’s important to have a national list.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right, and, I know that the top 10 primary languages have been suggested, and I think adopted by CMS, but they were suggested, as far as I know, originally by an organization called NHLP, which is the National Health Law Program; so, we can reach out to them and figure that out a little bit.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Great.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

So, are folks generally okay with t his concept, other adaptations, concerns? Okay. Let’s jump into advanced directives. So, this is the second line and, as you know, recording presence or absence was an option, a menu option for Stage 1 for hospitals. Policy Committee suggest that it’s a menu option for EPs as well in Stage 2, so, we’ll figure out later what the impact would be here. But, I think the key

difference is, that at this line is not about necessarily recording just the presence or absence, but facilitating the patient's ability to designate or to create their advanced directive on line and have it be stored and retrievable by providers. And so the POLST program is one way to do that.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

And Christine, do you know in that do they designate their proxy, too?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Yeah, this is Leslie, the difference between the POLST and an advanced directive is the POLST is the Physician Orders for Life-Sustaining Treatment; it includes the proxy and it includes a standing physician order. So, it really fits well into the EHR-world because there is an order associated with it and it gets to very specific data elements like intubation, nutrition and so forth, and, it is specific to "I'm active in care." An Advanced Directive is a document, generally a narrative. It could include a POLST and other things, but, it does also not necessarily have to be in the patient active in care, it can be on file, and it doesn't have to have a standing order. But both of these models would be great and, POLST is getting adopted quite rapidly for patients in care and then, I think, having the narrative document in place is just, if it doesn't come in Meaningful Use 2, we've got to have it in Meaningful Use 3.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

So, I mean, this is kind of... is this an alternative to the Advanced Directive?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

No, an Advanced Directive can include a POLST. A POLST is not a replacement for an Advanced Directive per se. So an Advanced Directive can assume both the patient active in care or a patient not active in care, it's my instructions.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

All right, okay.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

A POLST is based on a standing physician order and a patient active in care. The patient signs it, the doctor signs it and it's recorded as a standing order. So, they both address the needs of a patient in potential life-threatening situations, or life-ending situations or palliative care, but, it would be great to have both of these ideas included in Meaningful Use 3. And, the advantage of the POLST right now is that it is order-safe and an EMR does CPOE. So, there's that...

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

My only was like...depending on what sorts out that asks for the health care proxy, but, this alternative would be much more implementable as part of that process, so...

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Right.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay, so this is really actually two, I think, different things. So one would be require the capability in the EHR to document the POLST, is that the right language Leslie?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Yes.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay. And then the second would be provide patients with the ability to document their Advanced Directive online, in a way that's retrievable by providers, is that accurate?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Yes, or even if we couldn't get there, making sure that the actual document is scanned into the EHR, and once you have both of these things, we have to have a way to have revision management, proxy management access, so, there's things that need to be done under this, probably deserves an S&I sub-scheme to work on the technical capabilities. But, I think, so there's three things, there's get the narrative document into the record, which is the Advanced Directive, to have POLST integrated into the record within the orders system and then also to have a patient-reported or generated Advanced Directive that is interoperable in fact into the EHR. Does that make sense?

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yes. Okay, so what I have is two things, one is provide patients with the ability to document their Advanced Directive online in a way that's retrievable by providers and able to be incorporated into the EHR or at a minimum, ensure that the Advanced Directive document is scanned into the EHR. The second is, require the capability to document and integrate the POLST into the EHR.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Correct.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay. And then Leslie, you said we'll need a revision management strategy and you mostly sort of referred to the S&I team on the technical capabilities, is that essentially what we need, or is there any policy component to revision?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

I think we have to... this will be the first of many documents that have, for instance, in our care management or care coordination we'll have care plans that'll have multiple people revising, so, the idea of having multiple players revising a document, that function needs to be addressed in S&I framework. On a policy point of view, we need to be able to state that revisions happen and here's one instance, Advanced Directives is one, care plans will be another, but they do go hand-in-glove.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah, okay. All right, that makes a lot of sense.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

So, the question that we get challenged on in this space is that there are state by state variations of Advanced Directive. Is POLST, is there, does it have those same variations or is it standard?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Well, each of them can have slight differentiations or differences, but the POLST is being adopted quite rapidly nationally, but the idea that even if my Advanced Directive in Nevada is different from the one in Idaho, having it scanned and available shows that it's there and current. I think that having... knowing, is this the most current, what is our responsibility that it is most current is a policy issue...

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yes.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

...has to be taken up and that has to potentially look across more than state or we say, any state with a criteria that accommodates the following things, has to accommodate Advanced Directives in this way. So, we could...or provide exclusions for a state that doesn't accommodate it. But, I think we've got to address it and not just accept the fact that, boy this is hard... let's just figure out how to do it.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

I was just trying to see if there was an easier way, path to get the value, you know where I was going probably Leslie. The other question then, I think Christine you've got to reflect in there, I think, some of

the feedback we've heard in terms of operationalizing it is the point that Leslie brought up, is the currency and how do I make sure it's the most up-to-date.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

So, if there's a whole process, we scan it in, but all this stuff is probably not a process of managing around it and when you're making life and death decisions, people get really nervous.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right. Although...

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

I mean it's like with my parents, you try and say bring the piece of paper every single time because you don't know if it's going to be in the hospital...it's like, who knows? Who knows? So...

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right, although better to have something than nothing in a way, but... So, what I've done is to make clear that there is sort of a revision management strategy to make sure... that is needed to make sure that the care team knows it's the most up to date and then... which frankly, I actually think that one of the interesting registry reporting capabilities would be to have a registry of Advanced Directives so you can update it one time, in one place as a patient or caregiver and it's universally updated. But, that's maybe a different...

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

We support that, but...

**Christine Bechtel – National Partnership for Women & Families – Vice President**

...different subgroup.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Subgroup and maybe another slope.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah, exactly. So, but I also did note your guys comments around accommodating state laws or providing exclusions for state laws. But what I do like about this is that you can at least make sure that we're creating the capacity for the EHR to have the physician order for life-sustaining treatment. So I think having both is really good. Okay. Everybody good on that one?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

I do, and the other thing Christine is having a notion that a patient's direction can be incorporated in an order management system, when a physician agrees, is a really great leap to take, even though it's charts in Advanced Directive if... could set a precedent to demonstrate that patients involved in shared decision making with a physician can actually have things acted upon and reflected into their chart. So, this is a really good precedent to set.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Great. Okay, so the next one is record and transmit family health history. So, we'll have to revise once we know what happens with the Stage 2 stuff. I think that the issue here is that this could be something that might be required to be recorded, like demographics are, which is by the provider; or, it could be patient-generated or patient-reported data, where you have the ability to log in to either your portal or PHR and record your family health history in a structured way. So, how do we think through this one?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

So I think that the family health history for patient-generated data, along with whether it's demographics or surgical histories or any histories that I generate, is really a response for questionnaire that we could build upon that work that's been done. I think it's under the experience of care questionnaire has been defined under LOINC and potentially we could build on that, but, I think at a bare minimum, patient-generated data, it is in response to a questionnaire, whether its family history or demographics or social history or anything that a physician asks for, it's something we want to set that precedent for.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Christine, I mean this might be some worth getting a little bit more research. There are products in the marketplace which when you show up in the practice, you enter your assessment information, right, and there's no reason you can't enter that from home, right?

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

...with right authentication. So, there are products there, smoking, and ask those questions, so it's the whole, its more than family history, it's the whole health history that they . . .

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right, exactly.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

...should raise the bar. I mean, it's like... and we could certainly find out, not all, a lot of ambulatory vendors, they kind of add that on, those products onto their system and they capture it, but again, it takes the workload off the practice. Now the practice still has to own the accountability of looking at that data, right? But, it's certainly out there.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

So, I think the question in my mind is, how do we sort of record this, because what we're really talking about is a questionnaire capability that applies, or could apply, to family health history or, there's a lot of other elements, right, so, patient-created health goals, observations of daily living, things like that. So we can record this in our table here as, somehow trying to link these together so that what we're really trying to do is create the capacity of an EHR to collect the information, these varying types of information, and integrate it and here's a simple list of the kind of information that would be collected, or we leave them as they are, which is separate objectives around record and transmit family health history and its frankly up to the provider how they do that, if they buy the add-on that... and they have it adapted in a standard space way, or what.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Yeah, that's a good question.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

So I think that it would be great to harmonize, at least the questionnaire so that any question asked can be put back into the EHR easily.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

So, we could say that Meaningful Use 3 will accommodate a patient response to clinician... you know, information sought from the provider and as an example, this could be family health history, patient-entered data, etcetera, and those data elements should be standardized, so we get from it the normalization and standardization of the data elements, a structure for questionnaires and responses and a signal that this could be one of many things in the future that could be sought from a patient, generated...

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

For the floor, you'd do the floor then, I guess. This is Charlene (indiscernible) the floor

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Yeah.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

The other issue again, I think that has to be recognized is, at least in the current state, there's still a lot of suspicion about this patient-entered data and I think that's just going to occur for a while, so, but the systems just have to know how to manage that.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah, and one of my questions was, actually with respect to that, and I'm not completely sure that I buy into the notion, although I do understand it in particular use cases, but, most of what's in my EHR today or my medical record, is from me, it is patient reported. But, as we move to an environment where there is more and more data exchange, I guess . . . I get the need to do that. Now, someone has told me though that most EHRs, I think it was the folks over at Kaiser Permanente, told me that most EHRs do easily source data already. Do you know if that's the case Charlene?

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

I typically, what I don't know... here's the flow that I'm not sure that they do; we certainly know who the source of the information is, what I'm not sure is, based on the source, do we have the provisions to always do that reconciliation process?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

So anything that comes into the medical record and requires today some sort of acceptance, either that acceptance is automatic because there's been an order and that order has a result or an observation...

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Yup, exactly.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

...that comes back in. So, but when it is for a request for information and it comes in, the source is there, the time and the date stamp is there and usually some sort of an indicator of... some sort of an urgency indicator, does this need to be looked at right now, can it wait? Once that's reviewed, if the lab results comes in, it's reviewed, someone, generally the nurse in the workflow in the ambulatory setting clicks, say yes that it is accepted and goes in. In the hospital setting, it comes in in more of an automated workflow. So, we want to make sure that this stuff comes in in a way that's easy and ingestible into the workflow, but there's precedence set already, in EHR.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

So again, like Leslie was saying, was when... like we're looking at that stuff now, when labs come in, you accept them because you either have an order or it's a known source and the precedence is there. Now we're trying to figure out when allergies come in, can we just put them in or do we have to actually...and again, that's a thought process, it's a process we're kind of going through right now, in terms of just... culturally as well... and is the patient-entered data that same provisioning is going to have to be there, I

think. It's either accepted and/or stored separate... you know, some people even store them separate as opposed to including them. But at least they're indicated that the source is the patient when it's stored.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Correct.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay, great. I think I've captured that; and this is something we're going to have to kind of come back to and give some thought to as we keep moving forward, I think.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Yeah and I think, Christine, if they go out with that RFI again, I think that's going to be... if we ask that question correctly, it's like... I think it's going to be all over the map, but it's going to be an evolution.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Well, I think that what we... I think the first place we can get some feedback on that though is really the patient-generated data hearing that is being planned in June. So, that would be good and I think it makes a lot of sense for us to come back to some of these items once we have some better information from that. I mean, if I look at the next row, which is around the capability to incorporate patient-reported measures to things like functional status and patient experience, it's the same thing. You know, same issue, you need a standardized... or you need some part of a structure or an architecture for a questionnaire and you need standardized data elements that can be incorporated into the EHR and reported for quality measures. Right, so it's the same thing.

So perhaps for these kinds of ones, we should flag them at this point and say that we will revise after the patient-generated data hearing.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Yup.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Does that make sense to you guys? Okay.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

I don't know, Leslie, we've had, in the industry again, there's been experience on the third one, but the fourth one again, the patient certainly can... the SS-36, but it's really not so much in the EHRs, it's in, other dimensions, not so much in the electronic patient record.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

For quality measures?

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Well, for just health outcomes and that kind of thing. So, I mean, it's been out in the field for a long time, but, incorporation into the EHRs is still pretty immature.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right, right, right...

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

...so we could paint that someplace else. I'm not seeing that.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

You know, maybe we do the same sort of discussion that we've been doing on Quality Measures, it says, if the certified EHR is sending the information to either the patient's system for instance, and we can attest that that data has not been altered, so, it's going into a module, then we can do the patient-reported measures and the patient-specific dashboards in a way that's useful to the patient without the burden of

the EHR. So, take that same approach, that any of these things can be a module if the data source is coming from a certified EHR.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right, right. Which I think is more of a standards issue than a policy issue, right?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Well, we don't want to have the policy indicate that everything has to be done within the EHR because... because it creates too much of a burden. So, we want to make sure that the policy states a certified EHR must be the source of data, and you must attest that that data has not been altered. That would be a policy issue.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

But, it can show up in any module.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

I think ONC has language around that.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay, okay. So, I'll make some notes and then I'm going to leave it to you guys to suggest any revision that may need to be done. And so for now, what I've done is flag on this one and the one previously, you know, same kind of issues around the questionnaire needs to be... there needs to be some architecture and it needs to collect standardized data that can be... I think what you're saying is Leslie, either integrated back into or used by the EHR, right?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Yes.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay. All right, got it.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Because in many cases, it could be a separate store too, you know, so, yeah.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Or a module, right.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Yup.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Got it, I think, but you guys will tell me when you get this . . .

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

I know, I know.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

This is like the blueprint days Charlene. Okay, so the next one is recording LGBT status; actually, this should not say LGBT, it's probably more accurate to say SOGI, which is Sexual Orientation and Gender Identity. So, this is a part of demographics, and, this is...

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

...one of the things, I think, Christine is my concern is that the way demographics are in an EHR is that when it's a demographic item, it shows at the top of your screen, on every screen and so, there could be sensitivity there if we... so, we want to record the status absolutely, but... and have more granular data, but it could be that the sexual preference is actually stored in a clinical field and monitored differently, so, I would be hesitant to state it's demographics because it will be on the top of every screen.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

I see, so how would we...

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

I would just state that we want to record status and also have more granular race, ethnicity, language for IOM. And, we don't have to prescribe where it's available.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

You know, we're trying to get this 360 degree view of this patient Leslie. This is Charlene. It's tricky, this is a tricky space.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yup, it is tricky. Okay, so what I'm going to do is say, record SOGI status and, as part of demographics, more granular data on race, ethnicity and language, using the IOM standards or something like that, right?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Sounds great.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Is it the... IOM made the recommendation, what are the right standards.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Well, right, so, yes, that's a good point. So let me clarify that.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

IOM made the recommendations, but, we're struggling not to have the standards, I don't even know who owns the standards.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Well the problem, I think is, there are some standards that CDC owns that begin to operationalize and tie back to the OMB standards or the, like the information standards, not the data standards if you will. So, there are some...the CDC standards do do that and they do tie back, but I think there is a lot in the IOM stuff that I don't know that we have standards on and we are going to need the Standards Committee to weigh in. It's the same with SOGI data, in fact, it's probably in a more immature place in that there are examples of healthcare systems that are recording SOGI data, but they're doing it in different ways because there aren't a lot of standards and so, IOM is, right now, looking at the feasibility of doing a workshop, a one day workshop, where they would bring some of these health systems in and figure out how are they doing it, and sort of what's the action plan for coming to a set of consistent data specifications for the data, but then also, at the same time, methods for collecting that data, because

that's what we had to do on race, ethnicity, language and gender as well, was, we had to give providers some help on, how do you go about collecting this and what do you say when patients say, "why are you asking me these things?" So...

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Right, exactly.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay. All right, great. So, I think that's fairly... it's not easy, but, that row is anyway straightforward. So, that gets us into care coordination and communication. So the first one is a fairly general thing that needs some specificity, and that is, making information available to care team members across settings and providers; and I think what is meant here is the ability for the patient to actually send updates, to providers, to say, "hey, I wanted you to know that I have an updated medication list," or whatever the case may be. Is that a function that we want to have an EHR be able to integrate and a patient be able to do as part of view, download, transmit? Or is that already covered in Meaningful Use some way, I don't think it is.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Okay, so if there's a change to a medication... so let's take that scenario then, when it wouldn't it be covered by view, download and transmit, so... I meant, the only person that can change my medication would be my doctor's order, right?

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yes. But what if my specialist has put me on a new med, this is sort of what I'm thinking, specialist put me on a new med, let's say they're not a meaningful user, and they may have an EHR, but they don't, for whatever reason; so, if my specialist has me on a new med and I want an easy way for me to update my healthcare provider, my primary care doc, I mean secure messaging I guess would be one way.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

And it could also be, again, patient-generated data, it also could be a requirement that in that case, PBM data is shared with an EHR or multiple EHRs, and this gets back to the communication. So, if I'm, for instance, if I'm a clinician of record and I order a lab, I get a result. If I order a lab as a doctor and I say CC the following care team members, they also get the result. Now we're saying, what happens if I'm a patient and I'm the only one that knows that this change, how do I get that fact into the record, and it's back to patient-generated data, but it's also saying how do we identify all care team members and make sure that they are communicated with.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right, so this could be the case, if it's... there are a lot of situations, I think, Charlene. One of the things that you're raising is, there are a lot of situations where that update will happen on the provider side and be transparent. I'm also thinking of situations, like I have a physical therapist or I have a nutritionist or I have a, right, because patients define their care team very broadly or, I'm on a new OTC vitamin that I want my care team to know about. So, how do I kind of proactively publish that. So, it may be that what we do is reframe this a little bit and just say, provide patients the ability to send updated health information to care team members, and we need to come back to it after the patient-generated data... because I think there are a lot of situations where it's probably not going to be covered by the provider side. Because we can't count on everybody being a meaningful user, because there are lots of people who won't take Medicare, won't take Medicaid.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

It's really you download/transmit and report.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah, exactly.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

So you can report back in, and that starts to get to the patient-generated data.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah. So, do we want... is this something first of all that we want to keep in here? This is something that I think came out of the BPC use cases.

**W**

Yes.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

And my sense is yes, but I'm not sure that we know exactly enough, until... because the patient-generated data hearing, I think it is... Michelle, maybe you can record this as one question that I think would be helpful to get some thought on, is, okay, it is another form of patient-generated data, and it may have been that the original source is actually not me, but my doc, who put me on a new med or my physical therapist who started me on some OTC regimen, or whatever, but that, the patient has the ability to kind of make that part of their comprehensive record that their care team members get.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

I know when we start to get... this is just from an operational perspective, when we start to get into sending out those updates and who gets them and, maybe the specialist doesn't want them, it just gets... we've got to try, at least in these early stages, to try and keep this as simple as possible and make it work, because I know in terms of setting these up in other cases, there's just a lot of variability when and why people want... if the patient's back, I want the most current stuff, but I don't need to know every update, that kind of thing.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

So, that's... there are some operational challenges with implementing this, so...

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay. So, I'm recording those, those are good questions and we'll leave that in the notes field for something that we need to come back to, I think, and get some feedback on, because since none of us are doctors on the phone, it might be a smart idea. I think this actually something that Neil Calman could be very helpful with. So, the next one is kind of the flip of that, which is, the patient says, and Leslie help me with this but, the patient says to my specialist, okay, I want you to send a care summary to my primary care doc and copy me. Is that right? So that's cc me or designees.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Right, or send it to my family care giver. It's just all about getting that movement of any or all part of my record. So, if someone says, I'm going to order those labs for me, wait, can you cc me on that order, I'm the one who has to submit the specimen, I'd sure like to know about it.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

So this is a functionality that I think is good, and I think would make sense here. Do we need to talk about it further, is it clear? I mean, I think it's sort of like use the direct saying, we'll get the Standards Committee to weigh in on all this, so that would be helpful.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Yes, I think it's pretty clear.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay. The next is, identify patient-specific opportunities for enrollment in research and clinical trials. This one I have a lot of questions about, just because I don't know how . . . if it works today, if there is a centralized kind of listing of available, I don't think so, clinical trials for example or Leslie, maybe we mean something that is more simple, like this record, I have flagged myself as somebody who would like to do that. But, I don't know how this would sort of work in practice. Any thoughts there?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

This is a tough one, it's a tough one. So, in the research community, like AHIMA, they say, how do I get . . . I want to be able to identify the patients cohorts that I'm interested in and I want the nurse to be able to know what those cohorts are and offer that to the patient, and there's no mechanism for that. So, that's one part of it, on the research side of the house. The other part of it is, the patient states, "boy, I'd sure like to know if there's enrollment opportunities for me," and that's probably self-identifying, I want to identify myself. So there's . . . probably the harder thing to do is the research folks, but they're saying, "hey I really need this, how do we get to the heart of it," and at least for a patient to say, yes I am interested in research opportunities and having that flagged in an EHR would take us a long way.

**Kevin Larsen – Health & Human Services – Office of the National Coordinator**

Christine, this is Kevin Larsen.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Hi Kevin.

**Kevin Larsen – Health & Human Services – Office of the National Coordinator**

Hi. There are some places that do work like this, Cleveland Clinic for example, and there's, I think, as a patient as part of your entry, you're asked if it would be okay for you to be alerted to clinical trials that are appropriate to you. I could be wrong about that, but I know Cleveland Clinic has done a lot of work in this area. But my guess is that that is the suggestion, is that it's sort of a yes/no flag for a patient's chart; it's sort of like, send me information about trials that might apply or don't bother me.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah. Yeah. Okay, so this may be something that we . . . I mean, I think Kevin, when I listen to you, what I'm understanding is, you know, in my view, this could connect patients to NIH clinical trials, but my guess is that the Cleveland Clinic just connects into clinical trials that they have going on in their system?

**Kevin Larsen – Health & Human Services – Office of the National Coordinator**

Yeah, although . . . so there are some places of trials that are more broad, there are a few registries of rare diseases that span organizations; so, if you have cystic fibrosis, you might be in a multi-institution cystic fibrosis registry and then it could be a flag in the EHR that is passed to the registry, for example. So, across the country, you're sort of, hey this is someone who might be interested in a cystic fibrosis trial. And also certain specialties do this a lot more than others. So, for example, in the cancer realm, there is a goal to get as many cancer patients on clinical trials as possible, because so many cancers are fairly rare, in order to get enough people to understand that treatments are effective, they want to get most of the patients that would qualify asked if they could be part of that trial.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay.

**Kevin Larsen – Health & Human Services – Office of the National Coordinator**

Does that make sense?

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yes, absolutely. So, how do we get some feedback on this one? Because I don't think we have the folks on the phone who know everything about it, but there would be a good way to get some feedback from folks who say, okay, well is there a role here for the EHR or for the patient in the online access

component and what would that be. Because I think all we're trying to do is . . . we're not trying to make everybody like enroll in clinical trials, we're just trying to create a helpful capacity in an EHR.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

And I think that AHIMA might be able to help us, or trying to think of... at Intermountain Healthcare is pretty expert in this.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

And I know some of the vendors are... this varies quite extensively across the vendor community, some vendors are pretty aggressive in supporting this in their products and others are not. And PhRMAs also done just a boatload of thinking about this in terms of working with the community in doing some testing of, the standards and transactions to do those kind of inquiries. But it sounds like there's a progression at least as part of your patient preference list you start to indicate if a patient's interested in clinical trials... we could start, and then whether we support that there's a recruitment process, I mean, there's a lot of software around this space that's in or external to EHR is once that indication is given.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

That might help.

**Kevin Larsen – Health & Human Services – Office of the National Coordinator**

This is Kevin. You might reach out to the American Cancer Society or a group, there's a society of parents of children with rare diseases, those would be two groups that would probably have some more thoughtfulness about this from the consumer side.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

And you know, it should also be Lance Armstrong Foundation.

**Kevin Larsen – Health & Human Services – Office of the National Coordinator**

Yeah, exactly. It's groups like that that will likely have thought this through and say, this is what we recommend.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Right. Okay. All right. So, is that something, that kind of feedback, if I give... Michelle, if I give you my notes, is that something you can help us kind of solicit or do we need to do that on our own?

**Michelle Nelson- Office of the National Coordinator**

No, I can help.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Awesome. Okay, so we have about a minute left, I just looked, and we need to do public comment. So, let me make a suggestion for where we pick up on the next call, which is in two weeks. We'll pick up on the caregiver agent designee status and I wanted to suggest folks that take a look at caretransitions.org. That is a good place, they define DECAF and DECAF is essentially a coding for what kind of a role the caregiver plays in the patients care, so, do they do direct care provision, do they provide emotional support, do they do care coordination, do they do advocacy or do they do provide financial help; that's what DECAF stands for, and there is a one to three rating system that... where you can say, oh well, they provide a little bit of financial support so they're a one on the "F", and it really helps with care coordination transitions, caregivers support, identifying gaps for patients and things like that. So, take a look at that. And also...

**Michelle Nelson- Office of the National Coordinator**

Christine, this is Michelle, I'm sorry to interrupt you, we actually have until 4 o'clock, I don't know if other people are available, but...

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Oh, I don't think I am, actually. But, Charlene and... no that's okay, I mean I can do a few more minutes, I guess I don't... I don't know why my calendar appointment only has an hour. Charlene and Leslie, are you guys available?

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Yes.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay. All right, then let's do a couple more minutes and then we'll go to public comment, if that makes sense.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Sounds good.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

All right, well good, I was already talking about DECAF, so, DECAF is... what I like about it is that it is standardized, it's a standardized approach, there aren't necessarily technical data standards, but, Eric Coleman, they have built this capacity into their EHR and it would be a great thing to be able to have, and so, I think the criteria is for the... and again, this is one of those that could go either way; the provider could record the caregiver status of the patient and specify the caregivers role, or the patient could do that as well; and I think it's again, sort of a workflow issue. If we just say, somehow we would like these things to be recorded, you figure out if it's... what your workflow is that works for you. So, folks may want to... do you guys want to talk about the DECAF piece now, or do you want some time to kind of look at it on caretransitions.org?

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

I think we should look at it, but I mean, again, I think those are the kind of things that what you're suggesting makes a lot of sense in terms of... you know, as they're starting to emerge and be standardized tools to capture that information.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay, great. And Leslie I know also agrees, because we had a quick discussion about it earlier on email. Okay, so the next one is actually the big one, and so I do think we want to save this particular one for next time. But, let me give you sort of a sense of what's in here and ask you to look at it and send me any feedback that you guys have offline and we can kind of bring that together on our next call. So, this is view, download, transmit and now report, right, so that's what we just talked about. And not to say... we also need to have, I think, for patients, the ability to upload data. So, if they are able to download information from a specialist, and they would like to upload it into their portal, let's say that they have with their primary care provider, I'm not sure that's covered by view, download, transmit.

So, I wanted to flag that for folks to give some thought to, I'm not sure the best way to do it, but I think it is an important capacity and then what we've done here is to divide the kind of list into two sections, one is additional data that the patient could enter in, which would be family health history as we've talked about, medication questionnaires which would help with med reconciliation and creating an up to date med list; patient-created health goals, observations of daily living, caregiver status and role that we just talked about and also the list of care team members. I think patients know better than anybody, who they're seeing, so, an updated list of care team members, or at least the capacity to collect that data, would be very helpful.

The second part of the list is really what additional functions do we want online access to have, when it's displaying all of the data that it is already and it has the capability for downloading and transmitting, what

are the other capabilities, and so there's a list there that came from a combination of the BPC use cases and also the Tiger or Power Team, the Standards Committee's Power Team. So, take a look at those and see what you think, and then the rest of the table is, again, stuff that has come from one of those two places. So, on our next call, let's pick up with view, download, transmit and we will then dive into the . . . finish doing the rest of the table as well, and think about where we go from there, and then we'll actually address the two questions I have from the use cases. So, feel free to send notes, comments and thoughts in advance of the next call, but we'll walk through this in the next call if that sounds good. Does that sound good to folks?

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Sounds great to me.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay. So, then the last thing you'll see in the table is some areas for other subgroups to consider, that were based on either our conversations so far or from the Tiger Team, the Power Team rather, the Standards Committee's Power Team. So, I've flagged some things down there just so we don't lose them. So, feel free to add to that as well, things that you feel are related to patient and family engagement but maybe not in this particular subgroup. So, all right, any questions, comments or thoughts before we go to public comment? Oh you know what, I'm going to add one thing and I'll add it on the table that we send out to you guys, that's revised based on the call today, that is the ability, it's in one of the principles, and it's the ability to get recall, you know, get alerts for a drug recall, etcetera. So, I'll add that.

**W**

Great.

## **Public Comment**

**Christine Bechtel – National Partnership for Women & Families – Vice President**

All right, so let's go ahead and open the lines to public comment. MacKenzie?

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

You have the recalls, did you just have just general alerts and those kinds of things in there?

**Christine Bechtel – National Partnership for Women & Families – Vice President**

It's not, that's what we need to add, so if you have good language and can suggest it that would be great, especially since my computer just broke.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

(indiscernible) recalls but, you know, you get the prescription reminders from your drug store, but, you know, it's like, you could really remind... remind a person to overload; we don't want to go there, but.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Yeah, right.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

There should be . . . just like we sign up on our banks and want alerts for things, all those . . . like just enabling that front end to start to capturing their communication preferences and all that kind of stuff, you can start to see those . . . when do you want to be alerted, you know.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Great idea. Yeah. So what I just put in here is receive alerts for drug recalls, etcetera, and set preferences for alerts, and we can refine the language on the next call.

**Charlene Underwood – Siemens Medical – Director, Government & Industry Affairs**

Stuff they can start to set up when they enroll, right?

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Um hmm, right. Okay great. All right, let's do public comment.

**MacKenzie Robertson – Office of the National Coordinator**

Okay. Operator, can you open up the lines for public comment please?

**Caitlin Collins – Altarum Institute**

Yes. If you are on the phone and would like to make a public comment please press \*1 at this time. If you are listening via your computer speakers you may dial 1-877-705-2976 and press \*1 to be placed in the comment queue. We do not have any comments at this time.

**Christine Bechtel – National Partnership for Women & Families – Vice President**

Okay, well thanks everybody for joining us. Our next call is in about two weeks. We'll get a revised document of what we worked on today out to you this week and we will go from there and if you guys have feedback on the patient-generated data hearing, be sure you weigh in with that, if you're not on, there's an existing email train, if you're not on it, you can send me your feedback and I'll forward it in with any questions that we have based on today's conversation. Thanks everybody.

**Leslie Kelly Hall – Senior Vice President for Policy for Healthwise**

Thanks, bye.

**W**

Bye, bye.