



## HIT Policy Committee Consumer Workgroup Final Transcript March 11, 2015

### Presentation

#### Operator

All lines are bridged with the public.

#### Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Thank you. Good afternoon everyone, this is Michelle Consolazio with the Office of the National Coordinator. This is a meeting of the Health IT Policy Committee's Consumer Workgroup. This is a public call and there will be time for public comment at the end of the call. As a reminder, please state your name before speaking as this meeting is being transcribed and recorded. I will now take roll. Christine Bechtel?

#### Christine Bechtel, MA – President – Bechtel Health Advisory Group

I'm here.

#### Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi, Christine. Amy Berman? Brad Hesse? Clarke Ross?

#### Clarke Ross, MA, DPA – Public Policy Director – American Association on Health and Disability

Hello, I'm here.

#### Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hi, Clarke. Cynthia Baur?

#### Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention

Here.

#### Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology

Hello. Dana Alexander? Danielle Tarino?

**Danielle Tarino – Lead for Consumer Education, Health Information Technology Team – SAMHSA**  
Here.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**  
Hi, Danielle. Erin Mackay?

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**  
Here.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**  
Hi, Erin. Ivor Horn?

**Ivor Horn, MD, MPH – Medical Director, Center for Health Equity – Seattle Children’s Hospital**  
Here.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**  
Hi, Ivor. Kim Schoefield?

**Kim J. Schofield – Advocacy Chair – Lupus Foundation of America**  
Here.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**  
Hi, Kim. Leslie Kelly Hall?

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**  
Here.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**  
Hi, Leslie. Luis Belen? Luis, I always say his name wrong. MaryAnne Sterling?

**MaryAnne Sterling, CEA – Co-Founder – Connected Health Resources; Principal – Sterling Health IT Consulting, LLC**  
I’m here.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**  
Hi, MaryAnne. Nicholas Terry? Philip Marshall?

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**  
I’m here, good morning.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**

Hi, Philip. Teresa Zayas Caban?

**Teresa Zayas Caban, MS, PhD – Chief of Health IT Research – Agency for Healthcare Research and Quality**

I'm here.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**

Hello. Theresa Cark? No, I'm sorry, Theresa Hancock? Tripp Bradd? Wally Patawaran? Wendy Nilsen? Will Rice? And from ONC do we have Chitra Mohla?

**Chitra Mohla, MS – Director, Workforce Programs Office of Provider Adoption Support (OPAS) – Office of the National Coordinator for Health Information Technology**

I'm here.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**

Hi, Chitra. Anyone else from ONC on the line? Okay, with that I'll turn it back to you Christine.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Great. Well thanks everybody. I'm going to do a quick review of the agenda and we're going to dive right in because it is a totally packed agenda. Let's see, I just lost my web screen so can we advance the slides. Cool. So, as promised, we're going to talk about the interoperability roadmap; thank you very much for those of you who sent comments in on section C. We're going to dive into that today. We're going to start, of course, by talking about the consumer role in interoperability, as we had discussed last time.

So I'm eager to get started there and then we'll end with a quick sort of recap of we're going to do next with respect to section D and that slide is going to include some comments that folks had submitted that apply more to section D than they do to C. So, we have that to work forward to at the end. And then we'll have our next meeting, of course mark your calendar, its March 24 where we will actually review section D. So that's our agenda for today, but I want to talk a little bit about how we should approach this conversation, make sure you guys are comfortable, answer any questions you have, hear your ideas etcetera.

The roadmap is a big document, its 160 some odd or 80 some odd pages; I mean, who cares, it's a lot, right? So what we want to do is focus in, I think, on really providing feedback that is helpful and useful to ONC and that really identify some high leverage areas that the nation can tackle that will advance interoperability. So I presented yesterday to the Health IT Policy Committee; they asked each of the four workgroups that is working on interoperability roadmap comments to talk a little bit about their early discussions. So I characterized some of the themes that came up from our last call. I characterized some of the common themes that we received from you guys as workgroup members in the comments that you sent in last week. So we had a really nice discussion.

The feedback that I got from the Policy Committee, and by the way, thank you very much to Chitra for helping get ready for that and for doing hard work on the slides to get ready for today, after that discussion. So big thanks to her. The feedback that I got from the Policy Committee was really good. I think they were very interested in some of the comments, particularly around consumer role in interoperability. I characterized the hesitation we talked about on the previous call with respect to why are we asking consumers to demand their health information, they already have that right under HIPAA; that's not the right framing.

We just submitted comments on the strategic plan and we talked a lot about partnerships, you know, it means that we need to really reflect that new paradigm of partnership in the interoperability roadmap, both by changing the framing of demand, but also in looking at how section C and D might work more together. They really liked that approach, they thought that was good; there were a lot of nodding heads around the room. They...we also talked about the need to create parsimony that there are a ton of goals or calls to action across multiple different stakeholders in the next 2 years, so they're, I think, looking for ways to really prioritize to the high impact areas.

So that's something we want to think about today is, how do we create some parsimony in these calls to actions. There are definitely some additions that you guys have suggested which is great. We want to also look at ways to streamline and that will be an important part of our discussion today. And then finally, I think we were reminded that this is a nationwide roadmap, it's not just an ONC roadmap. And I thought that was a good reminder.

In terms of the level of detail I did ask Karen DeSalvo and the ONC's team yesterday about the level of detail that they would find helpful. And I think basically the answer to that is be practical, be tangible, be specific but don't get too in the weeds. So, for example, it's not appropriate for us to be naming standards or saying that this is the standard that should be used. So we really want to focus on the call to action and giving them feedback on that and staying at that level of granularity.

So what we'll do for the...I want to open it up for any questions or feedback or comments that you guys have, then we'll turn to a discussion and in the next several slides, we're going to talk about the consumer role in interoperability, we're going to go through the feedback that we've got from the workgroup members and our last discussion. Probably going to ask some of you guys from the workgroup to really weigh in and explain some of your comments and questions.

Then we're going to take today's conversation, condense it into a letter and in condensing it, I'm going to try to stay...work with Chitra to stay at that...the right level, create some streamlining in that and I'm also going to leverage the comments that we made on the strategic plan, which successfully got submitted to the Policy Committee yesterday in final form. So that...and they didn't change at all over what we recommended; so that's great. But there's a lot of relationship between the strategic plan and the roadmap so, we'll use those to draw out a letter that we'll get back to you guys before our next call. So, does that sound good you guys? Any questions or reactions to that? Okay, great.

Let's go to the next slide, please. Okay, so the charge that we've been given just as a reminder is to answer the questions that you can see on the right side of your screen. So are the actions the right ones to move us forward in the near term? What gaps are there? What...is the timing correct? Are these the right actors or stakeholders? And we're going to look again...we're going to start with section C. So that's just sort of a quick reminder for you guys; next slide.

All right, so we're going to start by talking about the consumer role in interoperability. I wanted to begin by reminding you of the definition of interoperability that is proposed in the roadmap; so you can see it on the screen. It's the ability of a system to exchange electronic health information with and use electronic health information from other systems without special effort on the part of the user. And then ONC goes on to say that in simple terms that means that everybody, their families, healthcare providers, individuals all have appropriate access to that information in a way that facilitates informed decision making and sort of the list goes on of actions that we could take based on that health information. So, any comments on that definition? I think we generally liked it last time, but let's reconfirm that and then we're going to go to the next slide and talk about the consumer role. Okay, great. So let's head to the next slide.

Okay, so I wanted to start with this slide because we had a comment from a workgroup member that I wasn't sure I understood, but essentially the comment, I just wanted to explore it with you guys, the comment was basically that consumer empowerment needed to be its own building block. So, I just wanted to check because we have an empower individuals in the center of the principles, so maybe that...we didn't quite understand the comment that was made, but I just wanted to double check that. The specific comment was consumer role should be highlighted with its own label as a building block. So, I can't remember who made that comment but I just wanted to double check that that...if that's covered or not by the empower individuals building block here?

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

Hi Christine, it's Cynthia; I think I made that comment and I think it was because of I think I gave the page reference where it was, it was in relation to particular diagram. I'm looking for where that is.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

Does somebody from ONC have those comments, because I think I referenced the page?

**W**

Which item?

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Chitra would, yeah. So you didn't...a principle in the blocks that are on the screen right now, you were talking about somewhere else?

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

Yes.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay. Well we can come back to that then...

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

Okay.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

...once Chitra finds it.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

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**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Of the roadmap?

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

Yeah, it was the roadmap. So this is...

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Ah.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

...this is where, right, where it's laid out in terms of the LHS, so this is how the roadmap is organized, business and technical requirements for a learning health system.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Got it.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

So that's a...kind of a different...I guess different slice than those principles.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah, you're absolutely right, it is. And I think what they've done is put the...well, wait a minute, hold on a minute

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

So that might raise sort of a different set of questions because I know on the call last time someone said, and I think I reiterated that in a couple of places, it's not really clear how the learning health system interacts with the notion of creating an interoperable nationwide system.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yes.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

And I just have a larger conceptual issue for the whole plan, not necessarily linked to our role in articulating the consumer piece. But it's just I think conceptually kind confusing because there is a table, and that's what I was questioning is, the two areas we were directed to look at, C and D, are listed as part of supportive business, clinical, cultural and regulatory environment. And my point was that that really obscures the whole role of consumers under that as a building block.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Right. Yeah and I don't disagree because it's really in that sort of cultural component. So I think that's a good comment to make, if folks agree with that. I mean, I'm not sure I would spend the time trying to figure out how to re-jigger it, but I do think it's worth saying that this is an issue. What do folks think?

**MaryAnne Sterling, CEA – Co-Founder – Connected Health Resources; Principal – Sterling Health IT Consulting, LLC**

Christine, this is MaryAnne; I completely agree. It almost seems as though we started down a path of interoperable systems, somehow we ended up with learning health system layered on top and it was not quite clear the interconnectivity of the two.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

And I think, Christine, back to your point about the slide is that it's really not clear to me now that you are making the link and saying, how did my comment relate to those principles. But I really don't get then how the table on 23 and 24 interact with those principles.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Right.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

Because these are the build...if 23 and 24 are the building blocks.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Well so I think the difference is that the building blocks are, like you need to have these things. But the principles govern the way those things happen. In other words, you need privacy and security, but you really need to build it on the existing health IT infrastructure, it's not rip and replace. We need to empower individuals within that building block, right? So I think that they are different and I think that's a good thing, because the principles do need to describe more about the kind of how it happens versus the what, which is the building blocks; one size does not fit all, simple, blah, blah, blah. So I'm okay with the difference there...

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

Okay.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

...but it is confusing.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

But I think to your point...to follow up on that then, I think what...if the empower individuals needs to be reflected in the building blocks then.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah, yeah, I completely take that comment; that makes complete sense now. Thank you for clarifying that. In terms of...so let's go to the next slide, because I think I actually have both these questions on the next slide, or at least...yeah, one of them which is so why...so somebody had said, why is the long-term goal learning health system rather than a fully interoperable system? My take on that, but I can't speak for the authors, is more, and I think it's...so my take on it is, much in the way that we said the Federal Strategic Plan should not be about collect, share and use health data, but it should be about like actually improving health, the Triple Aim, you know, person-centered care, things like that.

I think what they're saying is, you need an interoperable system...you need...you know, interoperability is the strategy but the end goal is really a learning health system not just an interoperable one, which I happen to agree with, if that's actually the correct interpretation. I don't know if anybody from ONC has the actual answer on that. Okay, maybe not, but what do you guys think of that?

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

This is Erin; I was interpreting it in the same way, Christine. I know Steve Posnack is a fan...a standards guy over there is a fan of always asking the question, interoperability for what? And for me, this was a way to answer that question, interoperability for what, not just for technologies sake but rather for the sake of the learning health system.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah. So is everybody okay with that or is that...do we feel like we need to make a comment on that?

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

Only similar...this is Cynthia; so only similar to the conversation we just had is that I think articulating the link that you both just did more clearly throughout the document would be helpful...

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

...because clearly some of us missed it.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yup, okay; that's fair enough. So, there were some other comments that folks made that I wanted to check with you guys about and ask you to explain as well, which is so first we heard from you guys that a realistic vision of what interoperability will or should like in 2024, if it's truly patient centric, then the patient will be the dominant curator of health information. And then the second thing that folks said was missing was a succinct explanation of the current and future barriers to interoperability. So, does anybody want to comment on that, maybe give us a little bit more insight as to the concerns or thoughts there?

**MaryAnne Sterling, CEA – Co-Founder – Connected Health Resources; Principal – Sterling Health IT Consulting, LLC**

Christine, this is MaryAnne; I don't know who made the comment, it was not me, about the barriers to interoperability but that is spot on. Now that I see it, I'm surprised that I didn't catch it along the way as well. I think that is a key component of this document.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay. Okay, got it, so just to say, look we need to catalog them and then make sure the calls to action are actually addressing them?

**MaryAnne Sterling, CEA – Co-Founder – Connected Health Resources; Principal – Sterling Health IT Consulting, LLC**

Absolutely.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay. Okay, great. So let's keep going. We'll go back to the authors and check in with them on those, but let's keep going for now. In terms of...next slide, sorry, that's what I mean by keep going. Okay, good. All right, there are two global comments that I wanted to make sure we address or mention so we'd talk about as a group if we need to up front, so that we don't have to keep repeating them everywhere, because they show up all over the place.

So one is, there are a lot of instances where it's like others...so individuals and others, but we need to actually say authorized family members or other authorized informal caregivers. That's the first comment. So I thought what we would do in the letter is make some kind of global comment and say, throughout the plan, first of all you need to recognize the essential role that family members play in interoperability and you need to be very careful about your language and we'll just have like a sentence or two on that. So, does anybody have any objection to that? I can't imagine you do. Okay.

So the second is a comment about care team and also care planning. I realize now, looking at that, that should say both care team and care planning; there's a third bullet that I think I lost somewhere in the shuffle here. So this comment is, I think, an important one for us to discuss. And this is essentially the notion comes out of the fact that there is a large segment of our population that does not think about care planning specifically with regard to how it applies to my healthcare, but rather comes from the approach of a person centered planning process more globally because it recognizes that healthcare is a piece of that plan, but it is not the only piece of that plan.

And so how we are particularly in an environment of interoperability, how we are recognizing that a planning process is inclusive of care but also connecting to community resources, long term services and supports and other kinds of services and supports. And so to that notion, there are two things I want to talk to...or want to double-check with the group that you guys are comfortable making this comment; one is that we need to think about the language we use with respect to care planning. Should we call it a person centered plan instead of the care plan? Second is the suggestion that we would replace some of the language about care team with services and supports teams. So I'll stop there, but I'm going to turn to Clarke, because I know you're on the phone, first and ask you if I've missed anything or if there's anything you want to add because you have such deep expertise in this area.

**Clarke Ross, MA, DPA – Public Policy Director – American Association on Health and Disability**

Well thank you, Christine. You always articulate these things verbally much better than I do; both of these were my suggestions based on the disability field, so I don't have anything to add to both your explanation and your question to the group. And thank you very much for including them.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Great. So thoughts...

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

Christine, this is Leslie, I have a question.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Sure.

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

Hello?

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yes, go ahead Leslie.

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

So one of the things I think the care and support services language, I wonder if a provider looking at that or a policy person looking at that would know that that meant the family and the patient and the families' support system. Because it sounds very provider and social services centric and not a care team, which includes the patient, their family or any other designee including non-traditional providers or support services.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah.

**Clarke Ross, MA, DPA – Public Policy Director – American Association on Health and Disability**

This is Clarke. I think there are two issues; one is defining what the services and supports are as opposed to care. The second then is who constitutes whatever we call the team, and I agree with your observations, Leslie, on making sure that everyone who is important to an individual's life have the opportunity to be part of the team.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah. So, let me make a suggestion...its Christine. I think Leslie's question is spot on and Clarke, I think you know that, too. So part of it may be an artifact of the fact that I've kind of pulled out the comment from where it was and positioned it as a global comment. It might be a better strategy to put it back in the context of where the comment was made so it's not like we're saying search and replace the word care team with services and support team throughout the roadmap, because I think that's going to be confusing for folks. But rather we'll go back through and maybe in the specific areas where that's important...where that's an important concept to reflect, we can reflect it there. Would that help?

**Ivor Horn, MD, MPH – Medical Director, Center for Health Equity – Seattle Children's Hospital**

Hi, this is Ivor. Can you give us an example of the place where you're talking about so we can put it in context a little bit?

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah, it'll take me a little bit to get to your co...to that, but...so you guys should keep talking but I'm going to look now.

**Ivor Horn, MD, MPH – Medical Director, Center for Health Equity – Seattle Children's Hospital**

And this is Ivor again, my question is in line with what Leslie's saying, is it an "and" rather than an "or" so that it's more inclusive? Because I agree, if I...as a provider if I say services and support team, it almost for me...initially it takes out the fam...the sort of core meaning of what we're talking about when we talk about the care team which is the patient and family and their support system.

**Clarke Ross, MA, DPA – Public Policy Director – American Association on Health and Disability**

This is Clarke. My idea was to replace care, which is a paternalistic, medically oriented concept in the disability field decisions made by professionals to care for you as opposed to assist you. But, I'd be comfortable as long as services and supports, the phrase is included, I'm...particularly, I know there's a paradigm shift going on between medically-oriented providers and people with disabilities struggling to live in the community.

So I'd be fine with care, services and supports, but my initial idea was to replace the paternalistic medical concept of care, I care for you, with I provide service and supports that you need in your daily life. So that was my motivation in doing that, but anything that adds services and supports to the existing terminology will be a step forward, away from the concept of dependent on care from the disability movement's perspective.

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

This is Erin. I'll just voice support for Christine's suggestion to look for some specific places where that concept, Clarke, is particularly relevant. Because I totally appreciate your points, but there are some populations that will receive...need to receive care under the paradigm that we have traditionally thought about it. I do like the idea of change...of a search and replace almost for losing the reference to care plan. I think a person centered plan, it's my opinion that that is...I think people...I think a large audience will understand what that means, even without the specific reference to care.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay, so its Christine; let me jump in and say, I found the spot and it's a call to action under C2, it's the third call to action and it says, "providers and technology developers should provide a majority of individuals with the ability to send and receive their health information and make decisions with the providers of the their choice, including but not limited to their existing care team, based on their preferences." And so the...I think we can just make a comment specific to this area, which is Clarke, where you made the original comment where we say, you need to...we really do need to recognize that that should include the services and supports team. Does that make sense?

**Clarke Ross, MA, DPA – Public Policy Director – American Association on Health and Disability**

Fine with me.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay. And I guess Clarke, I have a question for you though, is it...that call to action comes in the next two years? And what I want to know is that realistic or should we say by 2018 that the services and supports team, because they would have to have infrastructure to share information, receive information and I'm not sure that's...I don't know, you tell me, is that realistic in the next two years or should we put that in and say you've got to put this in 2018?

**Clarke Ross, MA, DPA – Public Policy Director – American Association on Health and Disability**

Ah, that's a difficult question. It's realistic in pockets of the country like right now and other pockets of the country, it could be many, many years away. So, I'm not a good one to assess the realism of when we're going to ch...but every forum the National Quality Forum, for example, we're moving in this direction, person centered focused on services and supports and person engagement. So...but I'm not the one who can answer that question on realism.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay. That's fine.

**Ivor Horn, MD, MPH – Medical Director, Center for Health Equity – Seattle Children's Hospital**

This is Ivor. From the provider perspective, I think when we put it in the full context of everything that providers are trying...that providers are required to do I think 2018 is more realistic. There may be some larger health systems with more resources that will have the capacity to do some of these things earlier and may be the leaders in that. And maybe we divide it out; I don't know but in terms of sort of the on the ground provider, I think 2015-2017 is really a tough call for them to have the capacity to do that.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay.

**Ivor Horn, MD, MPH – Medical Director, Center for Health Equity – Seattle Children's Hospital**

So I think...I agree with you, I think it should probably be moved to 2018.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay, I can work with that. So I will work with all of this with Chitra and we will get a draft and then you guys can react to it. If folks don't mind, if we could keep moving, because we have a ton of ground to cover, that would be great, but if anybody has any burning question or comment, interrupt me. Okay, let's keep moving to the next slide. All right, keep going.

Okay, so here we're going to dive in to section C even more specifically. And we do have a lot of ground to cover so let's keep our comments like as brief as possible and focused. And just so you know, the way that we have structured this slide deck is what you see on the screen now is the snapshot of everything that comes under C1, right? So this is the cultural change for individuals including demanding and using their health information. So this is what you see; the first column is like the next 2 years, the second column is the 2018-2020 and then the third is the 2021-2024, okay? So on the ne...so then what we've done is...go to the next slide.

Okay so here we're breaking out the workgroup's comments. So I'll go through them quickly on each slide; let's have a discussion and what I'd really like to hear is anything you don't agree with or anything that you might question the value of including, since it's going to be kind of a long letter. So, let's dive right in. I think we have enough, based on the last call, to draft a letter around this notion of the problem we have with consumers having to demand access, that that's not the right framework for the reasons I mentioned before; we want a partnership that suggests that we will access, again, this is the next 2 years. So I think we have enough there, although I'd welcome any other comments that you guys have.

There were a couple of other comments on this call to action that came from members; one is a proposed new call to action, you can see it on the screen, it's institutional purchasers and vendors should include individuals and caregivers in the co-creation of digital health information tools that can securely exchange health information. And again saying we really need to focus on use, not just access; so that could be access through VDT or Blue Button, portal or any other method, an App, whatever, but we need to really focus on use, which I happen to agree with. And then finally a bullet around consumer education being...understanding their rights and delivered in a language and file format of their choice. I might suggest that that move to another more appropriate spot, but I wanted to include it for discussion. So, reactions to what's here. If everybody agrees, we'll keep moving; but any questions or disagreement or anything that you go, I'm not sure we really need to say that.

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

Christine, this is Erin. Can you just help me understand how we'll incorporate both the change to majority of individuals and their caregivers will use access and then also emphasizing the use of that access?

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah. So I think my suggestion here would be that we just have a paragraph where we just explain our concerns. So first we might start with our concerns around demand and then we should say, access is great but you also need to focus on use of...

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

Okay.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

...health information. So I think it's an "and" also and not an either/or. Does that answer your question Erin?

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

Yup, that sound's good. Thank you.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Great. All right, any other comments? Okay, so the second call to action here is increasing the proportion of individuals that demand and ask for; so what they're trying to do is say that in the next 2 years a majority of people will, what we're saying, use their health information and then that somehow is getting increased. So that makes sense to me but the comment is, look by 2018-2020 then information should be useful and delivered in a language of choice. And I agree with that because that's how you're going to get from a majority to an increasing number. So, I think...so that's the comment we'd make there. Any thoughts or comments on that? Okay, great; next slide.

All right, so this is the third call to action in the same vein which is by...oh no, this is...I'm sorry, this is still in the mid-range timeframe; so the third call to action in this section is that individuals should contribute clinically relevant patient-generated health data and request corrections to their electronic health information to effectively manage their interactions with the delivery system and manage their health and wellness where they live, work and play.

So the comment here is, look, we already have the ability to request corrections, and I agree with that; what I've added in there is the issue is how to implement. And so Leslie will remember the long discussions we had when we were both on the Meaningful Use Workgroup where we proposed that we needed to give patients an easy way for them to request corrections in the record. I'd like to also suggest that we go a little bit beyond that and say that I think and this is an important construct I want to check with you guys. When we start thinking about the mental construct of this call to action, it's about me contributing health information. It feels, to me, like a paradigm of thought that is rapidly becoming outdated because when I think about the fact that I have 3 portals, I'm going to download...and those portals don't talk to each other but I can make that information come to me.

If I'm going to aggregate information from my 3 portals, I'm going to add information from a wearable, but I'm also going to add information from minute clinic, because I went last week and got a pneumonia shot and had them check out a rash, or whatever. And so I'm thinking back to the earlier slide deck where someone made the comment that look, we're really going to a place where consumers will be curators of their data, this notion of I'm going to just contribute data, which feels like I'm contributing to somebody else's database or EHR feels a little bit outdated.

So if consumers are in that role and I spot errors in my data, then I shouldn't only have an ability to request a correction, but I should also have the ability to flag that data in the record that I'm keeping so that when I share that with another provider or member from the services and support team, they can see that I have an issue with that piece of data. So that's the comment I'd like to add here and I wanted to know what you guys think of that?

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

Hey Christine, it's Phil Marshall. So I have some thoughts on that. So we've been in a large primary care pilot now, sort of with automated outreach to gather and analyze patient-generated data, to bring that back to the EHR and it's given us a lot of learnings on this. And we did...I've done a lot of focus groups here and the sort of observation that I've made related to your comment is that it seems to me, and I used to be in the...realm and was a big advocate for patients sort of being their own, you know, repository; that patients are eager to support their relationship with their provider and delivery system and want their provider to have all the data, including their minute clinic visit information.

But it certainly doesn't seem to be any longer that patients really desire to be the repository themselves; they want to enable that relationship with as much data as they can. So that's kind of my observation on that, so I don't necessarily agree that enabling the provider to have what they need for decision making is outdated, not exactly what you were saying, but I think along those lines. So that's just what I would add there.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

That's a really fair point. I think it's like, when they say there's any medication only works for like 80% of patients or whatever it is, it's the same thing, right? So there are probably...there's a big percentage that doesn't want to be the repository but as you said, wants to enable that information and facilitate that flow. And then there are other people who will want to be the repository and will also facilitate the flow; so I think that's an important distinction to make and I'm happy to include that. Are you also comfortable with this idea that we...by...in the 2018-2020 window, we need to have that ability for consumers to flag data that they think is incorrect before it's shared or something like that?

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

This is Leslie, Christine; I agree that not only will the patient act as an exchange if they choose to, but this idea of curating that we use. Curating also requires opinion of the person providing that information. So I think it's realistic and reasonable to say, the patient might send information, and that information shows that it hasn't been touched by anybody and it's really information coming and absolutely genuine from provider number 1. However, I'd like to comment on that, as a patient and say, I disagree with the following although both my opinion and this opinion is necessary for care, acknowledge that, but here's my opinion. So ability to add a comment of any kind to records the patient may forward, I think would quite important.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay, great. Thank you.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

This is Cynthia. I'm with Phil on his comments there and even though it's a very over-used word, I really think that partner is kind of a better choice to allow sort of for this range of participation than curate. Because I thought maybe co-curate could be it, but I still think that implies a level of activity that I think I would agree with Phil about.

And so I wonder, too, back to the discussion we had about principles, how...if partnering really is sort of the key...the core of this relationship we're talking about that goes back to the principles being about empowering individuals. So, it seems to me that partner ought...or whatever term, whether it's partner, co-creator or whatever, that should also go back and be reflected in the principles and then in those building blocks so that the language is used consistently throughout the document so you're not confusing people with, well what exactly is the nature of this relationship we're talking about.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay, great. I think...and I think inherent to what you were saying, at least in the first part of your comment is that there is a range and we just need to enable...we need to empower consumers across the range, recognizing there is a range. And there will be some people who don't want anything to do with their data and there will be people who want to completely be the curators and then there's everybody in between. So, I think I can get that in...I think I get the concept and we can get it in the letter for you guys to react to. All right, any other comments on this one? All right, let's go to the next slide.

**MaryAnne Sterling, CEA – Co-Founder – Connected Health Resources; Principal – Sterling Health IT Consulting, LLC**

Christine, this is MaryAnne, sorry, just a little slow on the mute button there.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

That's okay, go...

**MaryAnne Sterling, CEA – Co-Founder – Connected Health Resources; Principal – Sterling Health IT Consulting, LLC**

I think too that we need to figure out though where we want to go with this to a certain extent. Maybe this is for future discussion...thought, meaning, we talk about person centered care and empowered patients and empowered consumers and it feels like we need to be moving in the direction of patients and family caregivers curating, if you will bad word, but curating their health information in light of a lot of things; shortages of providers across the board. You can really make a case for this and I wonder if there's, you know, Christine maybe the language you were suggesting, do we know there's a range of people who are comfortable and people who are not with this concept? But we really need to push and enable those who are comfortable or who want to be comfortable curating their health information for a multitude of reasons.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah, so maybe one way to think about that is that we need to design for both ends of the spectrum, so there should be tools available that help people be 100% curators and there need to be tools available that make it easy for people who don't really want to have much, if anything, to do with their data to interact with it when they need to. And that's it, if you can do...if you can cover them plus the other end of the spectrum, then you've pretty much got everybody in between. Does that...what do you guys think of that?

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

This is Cynthia and I do, I mean I agree with you MaryAnne, but here's what I worry about is that we already have a system, a health insurance system, a healthcare system, a health information system, we already have a whole bunch of systems that are geared towards the high end, for the high performers, and that's what's generated the health literacy problems we have today. So that's why I'm really worried about kind of designing and pushing the envelope ahead based on this notion of curation when I think that's just going to be a niche in the market. I just see that as kind of a very specialized group of people who really want to be the quantified self. So that's what I'm worried about.

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

Well, I would jump in Cynthia, its Phil; I would jump in and say that I agree with the principle of what you're saying. However, when it comes to contributing your information into an environment like the provider environment, supporting ongoing collaborative and continuous decision making is something that doesn't necessarily require somebody to be a quantified self person, it really just requires for hypertension to have a...blood pressure cuff really.

And so I would kind of break those two ideas apart a little bit and one is are patients really going to need tools or do they even want tools to become their own curator. I would caution to say I haven't seen a lot of desire for people to want to have to serve that role; what they really want is they want all their delivery system to be on the same page. And on the other side that it really probably will be the mainstream people contributing regularly their data into that decision making process. So I thought I'd just jump in there on that one.

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

And I agree with you, Phil, that's why I prefer words more like participation or partnership as opposed to curation.

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

Right, that makes sense to me.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

So it's Christine; so let's...I'm reminded of a conversation we actually had yesterday in the Policy Committee and something that I recently heard David Brailer say, who a lot of you know, is our...was our first National Coordinator for Health IT and now does venture capital work with health IT companies. I think, it's like the construct of patient-generated health data where I think when it first came...became sort of popular and in our lexicon 18 months ago, it was all about well I have data from my device that I'm going to add to your data over there. And then the construct is starting to shift where...it's just shifting in a much broader way where some people are taking much more ownership and would like to have more control over their data all the way down to folks who have implants inside them and want the data from their implant in their own device that they can then share back with their clinician.

So, it reminds me that there's a huge range of people we're trying to design for, number 1 and that this market is evolving completely rapidly in ways that we can't predict, including the potential that we might see the day when people don't want to have to curate their own data including, by the way, their privacy preferences, but they might hire intermediaries who will curate the data for them and act on their behalf according to their preferences.

We have no idea so I think in this section, what I'd like to do is, I'll take a stab with Chitra at writing out how there's just a huge spectrum and diversity of roles, there's a spectrum and diversity of capabilities that people will even be able to do, let alone what they want to do, and we don't know where the market is going. But there are...I think we need to hone in on some key functionalities that someone needs to be able to do; one is flag things that you just viewed, another is make a comment, things like that that relate to what happens when data moves around the system.

Would it be okay for me to go ahead, if you guys agree with that, we can draft that up and then give you guys a whack at it so you can make some edits? Is that a good approach or did I miss anything in my characterization that I should include or get anything wrong?

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

This is Cynthia, I think that's great, I think that's very nuanced and recognizes the complexity of what we've all been trying to explain, I think.

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

And Christine, it's Phil again; I missed a chunk of the call so just tell me if you've already covered this but are you suggesting, I don't have the slides up in front of me, are you suggesting that patients would be able to in any way stand in the way of covered entities sharing data that they have? I just heard something earlier that kind of raised that flag in my mind.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

No, I'm not suggesting that. I think that's, first of all, I think that's a really broad statement, so I can't even...it's like hard to react to because I already have that right, depending on the purpose for which they're sharing it, right? If it's treatment, payment or operations no, but in other circumstances I do; so, I think that I'm not going there at all, but I think that part of data curation is managing my sensitive health information, managing my privacy and forget the word curation, part of empowerment is my ability to say, I don't want this piece of information shared, I don't think that piece of information is accurate and here's the information that I know you're missing that you are going to want for my care, right?

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

Okay, yeah, I just wanted to better understand that. Thanks.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah, no, no problem; I would not wade into the shark-infested waters that easily...

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

I'm guessing not.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay. All right, so the next slide is the fourth call to action under that 2018...oh, I'm sorry, can you go back one slide, please? We already zipped forward; thank you so much. So 2018-2020 has a call to action that individuals and their extended care teams, including family and caregivers, should utilize care planning to capture individual goals and preferences as part of the longitudinal health information used across care settings. So, a couple of comments here; one is, this is where we would have made comments about calling this a person centered plan. Two, we would talk about the definition of extended teams, which would be care but also services and support.

In addition, I think there's been strong support for this goal and this concept, but a lot of you basically said, why are we waiting until 2018; this should be happening now. There were some elements of Meaningful Use that supported collecting goals. So what I'd like to do here is basically say, remind about our language, number 1. Number 2, say this is already...this needs to be accelerated sooner, because this is a huge use case for interoperability, if you ask me. And number 3, harken back to the comments that we made in the strategic plan around that partnership and aligning to shared health goals.

So if we can use that, then I think here...that would be a great comment here to say, move this up, gotta get it done sooner and this needs to be shared health and care goals, and talk about the language. So, reactions to that? Before you guys react actually I'm going to say one more thing. There's a comment on the next piece below which is about regularly accessing and contributing health information that I think is meant to build on the care planning piece. And what I'd like to do is there's a comment on the right side that says person centered and care planning should work seamlessly together and must include social determinants of health. I'd like to suggest that the social determinants of health comes into the 2018-2020 goal and then the, everybody's using care plans backs up into the next 2-year goal. So, reaction.

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

This is Erin, Christine; I support those suggestions and was just going to add, if you thought it was helpful as an additional reason to or...a reason that we are recommending accelerating care plan functionality is that developing that kind of functionality and making it widely available will be critical to the success of new models of care, like accountable care organizations, that are already underway and both the providers and patients and individuals and larger care teams need these tools.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Great.

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

And this is Leslie; I would add to that that it's not just goals and preference but it's also specific direction that a patient can offer; this is, I won't do this, I do want that. And advance directives fall under this, so I want to make sure that's called out as a potential for patients to actually generate care plans or care planning, in the form of specific direction.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

So Leslie, you're bringing up some issues that we've been...we've struggled with, right, in Meaningful Use for all the reasons we know. Right now Meaningful Use has the ability to record...an EHR has the ability to record presence or absence, but not the actual advance directive. So I want to be clear, you're suggesting that the content of an advanced directive would fit in the care plan, which I completely agree with, is that in the next 2015-2017, is that realistic? Or are we saying along with social determinants of health and whatever else you guys want to suggest, the care plan...the person centered plan must include advance directive content in the next term window of 2018-2020?

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

I would like to see it sooner, I think that most organizations once that they guess there is an advance directive, they are recording it, so I'd like to...I think it's very possible and doable to do it more immediately, and it sets the stage for not only here are my goals, here are my objectives, but here is my direction and I think that is an important concept in care planning. It isn't just a rec...we're not just a recipient; we also have the ability to set direction of patients.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay, great. Other thoughts on this one? Okay, terrific. So 20...the other thing I'll flag, and we can come back to it is there's a core data set that has been proposed and it's going to show up on slide in a little bit here. We might think about some things like social determinants of health that are not ready right now, and probably won't be in the next 2 years within a person centered plan, we should maybe build that list and use this as another place to suggest the key, really person centered elements that need to be in that plan in the 2018 window. Okay. All right, great; so, next slide.

All right, oh and speaking of the common clinical data set, here it is. So, this is the overarching framing slid here, so let's go to the next slide or preview slide I guess you would call it. All right, perfect. So here's the common clinical data set on the left side of your screen as proposed. A couple of you guys made some comments around some gaps that we've put on the right side, that seem to be missing from the left side. So things like goals for care, advance directives, I'm not sure what value based direction is, but we can talk about that, a listing of who is on the care, caregiver services and supports team.

Also that for race, ethnicity, language, there are some better standards out there that are more granular for race, ethnicity and language today that come out...there's HHS, OMB and then of course the IOM standards; so, trying to shift to those; social determinants of health, community living and related social factors identified by the individuals. So, I want to talk a little bit more about what that means to folks. So, what do you guys think of what's here, what's missing and when you make your comments, if you could talk about what we're ready for now, which would be in the 2015-17 window versus what we think we can be ready for in the next term window versus what is longer term; that would be great.

**MaryAnne Sterling, CEA – Co-Founder – Connected Health Resources; Principal – Sterling Health IT Consulting, LLC**

Christine, this is MaryAnne and I think first and foremost we're missing identification of the family caregiver and that probably was alluded to in that third bullet, caregiver/support team, but we're at the point now where we should be able to identify the family caregiver, if there is one, their name, their role in caring for that person and their contact information.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay, great; perfect and that's in the current window of time, 2015-17, I agree.

**MaryAnne Sterling, CEA – Co-Founder – Connected Health Resources; Principal – Sterling Health IT Consulting, LLC**

Yeah.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

And I think we put some stuff in Stage 3 Meaningful Use, but I can't remember, so, we'll check on that one.

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

This is Erin, I'll just note that I feel really strongly that there is a gap with regard to goals for care, but that the existing common clinical data set includes a references goals as part of a care plan field and so perhaps or comment is not...is more about that both clinical and personal individual goals for health or care or life are included in this...that we're capturing both the clinical and the individual goals in the common clinical data set.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay.

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

This is Leslie, I totally agree with that.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Both individual and clinical, yeah; great, thank you. Other things missing from the common data set, advance directives obviously...

**M**

Well, it's probably under the assumption that...or at least one of the...

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Is somebody trying to talk or is that...because if you are, it's hard to hear. Okay. So anybody want to weigh in on what value based direction means? Leslie, I think that might have come from you.

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

Yeah, what I was trying to get at is with the example for instance, perhaps my values in my religious preferences will not allow me to use blood by-products. So my goals of care include the following treatment, but my values indicate that I would say no to the following things. That might be a stretch out in the future with advance directives, early on because advance directives are very concrete, we've already got the POLST, the MOLST, it's really a lot of work done, feel more confident with that. The value based direction would be something we could do in the future when we have a taxonomy to support those kinds of values.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay, that makes real...that makes great sense. All righty, all right, any other comments on this and, yeah, any other comments? Okay, great, we're making good progress; next slide, please. All right, so this is the kind of preview slide for the C2 section, so let's go one more slide. All right, so, in this section the first call to action is ONC, government and industry will identify best practices for incorporating PGHD. First of all I feel like this is the second mention of PGHD like we should just get one call to action so we don't overwhelm people around patient-generated health data. The second comment that you guys made, and I completely agree, is look, we've already done a whole lot of work here to identify the value and the workflow and some of the challenges and approaches to implementing PGHD, so this isn't really about best practices right now, in the next couple of years, as much as it is making it happen.

I would love to hear from you guys what the next step is that we need to take to make more patient-generated health data a reality; it might be that more providers are selecting the option...PGHD as an option in Stage, or at least it's been proposed, we'll see about the first rule that comes out soon, it's been proposed for Meaningful Use 3. What else do we need to do with respect patient-generated health data?

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

Christine, so it's Phil. So I'm not so sure about needing to get past best practices right into how do we make it happen because when I talk to folks, even folks in the biggest, most advanced and forward thinking health systems in the country, patient-generated health data is a real head scratcher. And so I actually don't think there's any understanding of best practices.

I'll give you a real clear example, when people are thinking about biometric devices or the Apple Watch or whatever it might be, all they can picture is really a deluge of data coming at them at all times and being liable for all of those data points. And yet they're completely unprepared for utilizing any of them until the patient comes back into the office anyway. They haven't changed their practices into anything more continuous or collaborative. And so what we're seeing as best practices are things like summarizing that on a regular basis that's acceptable to the care team and their workflow and incorporating it into the EHR in certain ways. And some of those best practices, I think they're completely unbeknownst to most anybody who's really considering patient-generated health data, even the EPICs, Mayos and Apples of the world. So, I do think there's a role for best practice propagation here as well.

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

This is Leslie; I would add that there is, perhaps we don't think of it as patient-generated health data but it goes on every single day and that's when we're asked to fill out forms or questionnaires. And in the testimony we've heard in the past, there's no argument or confusion from a provider who says, well I want to know your med history, give that to me. But I want to know a change in your insurance, give that to me. And that kind of ongoing dialogue using questionnaires in a patient's response back into the record is something that we should be encouraging and asking for right now because it's being done, it is...people don't even think of it as patient-generated health data, they just think of it as another way to gather history. But that's very, very meaningful and important.

As we move to patient initiated exchange, where there hasn't been a question asked of it, that's where we get into the areas of more confusion...do I really want to see your Fitbit information unsolicited from me? Perhaps not, but if the provider says look, I'm sending you home with a Fitbit or I'm sending you home with this device and I'd like to see a summary every week, there is no argument there. So I think if we focused on patient response to questionnaires initially for shared decision making, for advance directives, for history, for medications, for adherence information, we have a big win for everybody. In fact one provider that provided testimony, I think it was from Geisinger said, I'm a better doctor because I now have more accurate information. And I think that's where we can say, do this now. For best practices areas and future thinking, I think it's patient initiated patient-generated health data. Does that help provide a distinction between the two?

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

So what in your mind is patient initiated health data?

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

It would be done without any sort of question asked from the provider. It's, I'm sending you my data dump of my Fitbit, which is what we hear over and over, hey, that's going to be overwhelming. But when you say hey, it's the provider, when you ask a question of the patient, I want to know this, I want to know your med history, I want to know your new insurance information, I want to know if you're adhering to the drugs I've prescribed; there's no argument. And that really...that is also patient-generated health data.

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

You know what's interesting, the phrase physician requested patient-generated health data was in the initial Meaningful Use Stage 3 recommendation and I thought that was an important distinction but not necessary...it's not just forms, I mean, the physician may ask for your blood pressure results over the last month, right, so that's physician requested patient-generated health data just as much as a health history form. And I thought that that was a useful distinction. Maybe Christine you can reflect on sort of that...where that stands, that idea of physician requested and the importance of it.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah, I mean I think I have a way to bridge or combine what you and Leslie are saying. So what the Policy Committee suggested in Meaningful Use Stage 3 was exactly this idea of physician requested, right? It has to be because it's a menu item, so they have to pick it, they have to decide do they want to do a questionnaire, which is what we sugg...we proposed would be in there was one option was a questionnaire. Another option was using secure messaging, so it again has to be physician requested and then the third option was, if you're already doing something with devices, if you already have that feed, that can count.

So I think the way I might combine or ref...or make a comment that reflects both of your ideas would be one that we say look, we support the emphasis on patient-generated health data, that at this point we need to focus on implementing best practices and identifying new ones beyond those we already have. The second thing I would say is the provider should select the menu option for PGHD in Meaningful Use, if it gets included in the final reg and that vendors need to design that functionality so that it's highly useable and useful for both patients and providers. Because that's my concern is just because you put it in Meaningful Use doesn't mean the function that the EHR company puts in is actually like useful.

And then the third piece is that I heard you guys talk about is devices; this is a big source of PGHD with a very rapidly growing market. So the third suggestion I would make for our comments would be that we need to solve the standards war that is currently happening and we need to do that by 2018, because the device market and the wearables market is simply growing too fast; we need to get our act together. So that would be my a little more aggressive stance, but what do you guys think as a group?

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

This is Erin. I just wanted to jump in because I'm pretty sure this was a comment that I made and Phil, I think your point about that the average on the ground providers don't have these best practices in place is a really important one and a very good one and I don't disagree. I think where I was coming at it was ONC's already convened...they've already released white papers; I don't think it's acceptable in the next 3 years for them to sort of rehash that existing work. I don't want another white paper, that's not moving the ball fast enough for me, but I like, Christine, your suggestion to shift the focus to implementing best practices and identifying new ones. So I'm...that addresses my concern.

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

Right. Yeah, I totally agree with that, that's great.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay.

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

Although, can I ask, so you talk about all the white papers, like all the stuff I'm talking with people about incorporating patient-generated health data at the point of care and supporting more continuous relationships with patients, blah, blah, blah; I haven't seen anybody reference a well published and well referenced white paper on that best practice before, but maybe...I don't know.

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

I think there was...the National eHealth Collaborative did a paper on patient-generated health data for the ONC that used testimony from Geisinger, Kaiser, Group Health and several others. And I think...believe that's available on the ONC website. And then most recently there is a discussion paper on the topic coming out of HIMSS about patient-generated health data that might...

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

I think also one from RTI, but I could be wrong on that. And Erin, you served on the TEP also so...

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

Yeah, I think several of us actually served on that TEP, so that is the one I was thinking of but, maybe it's not...maybe those white papers don't really...didn't do a great job of listing things as best practices. I think I just want ONC to build on existing work and not use these 3 years...we just need to be moving the ball forward, but I...

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

I got it.

**Erin Mackay, MPH – Associate Director, Health Information Technology Programs – National Partnership for Women & Families**

Okay.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yup, I totally got it.

**Philip Marshall, MD, MPH – Founder and Chief Product Officer – Conversa Health**

Yeah.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Other stuff on this slide? I think I have a good sense of where you guys are at. The other stuff on this slide is again in the short term, so...and I think it is important. The proposed call to action is encouraging...having providers encourage their patients to access their health information online and will enable patients to view, download and transmit that information to the destination of the patient's choice. So I agree with that, I think we have a new call to action proposed, so providers should identify and remove barriers so that patients can view, download and transmit information.

We also had a suggestion that I think is a great one around set and forget, which is kind of this auto Blue Button piece so that you can say, look, anytime you upload new information to my portal, a copy automatically needs to get forwarded to my HealthVault account, I'm making that up. And then, right, so, supporting providers as they help educate patients and family members so that they're comfortable using those tools. So any comments there; this is all in the short term. I think essentially we agree and we might just nuance and so we can build off the comments that are there.

The next call to action is also in the same time window and it has to do with providers and technology developers that they need to give a majority of individuals the ability to send and receive. So I agree, I think, with that. So the first call to action right is providers encourage us to do it, but the second one is that we actually have the tools to do it and so I think that's right. And we had a comment from a workgroup member that said, technology developers should be creating open tools that allow the consumer to easily send and receive their health information and they need to do that with the input of consumers. Any comments on that, agreement, disagreement, whatever; actually I'm going to assume silence is agreement so if you disagree or have a nuance speak up. Okay, great; next slide.

Okay, so this is again, in the immediate timeframe and it's ONC working with technology community to increase the use of Blue Button by implementing a portfolio of standards that support consistency in the way individuals receive information. So we have some reframing there that, I'm trying to discern the difference, oh, okay, it's removing the use of the word...the reference to Blue Button because I think there's some concern that that term is not evergreen, although this is only in the next 2 years, so I think if we're comfortable with that, I might just leave it. And then second is the addition of patient education material tied to VDT, set and forget, etcetera. I'm not sure this is, again, the right...I don't think this is the right place, I think probably the last slide was the right place, but close enough, the comment's still valid. Any comments there? Okay; all right.

So the next call to action, again in the immediate time window is, ensuring that patients understand their abilities to access, send and receive. So again, I think this is an area where they've got a lot of calls to action that are extremely tightly linked to each other, right? We started here which is the demand, access to their health information and we said, look, they need to actually use it. So this is again not just about understanding, but also about use so I'd like to suggest that some of these don't need to be repeated so many times. That we need to have one or two that are kind of tightly focused, if that makes sense to you guys.

And so that's my first question and then, I think the real comments in the box are about we need toolkits for providers that follow health literacy standards and digital health...we need a digital health literacy initiative and then also a suggestion around the top five languages nationally, which is, I think, Leslie I know I think that's you, did you mean patient education materials in the top 5 language or the actual health information in VDT?

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

I'm talking about patient education materials attached to the VDT because the technologies there to say, even if your download is in English, the codes associated with it allow you to attach to the appropriate education in Spanish or Chinese or with the language, the top 5 language. So I think we need to start inserting this idea that its more than just English and Spanish but opportunities to do...just do much, much more with education.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Got it. Okay, great; thanks, that's a really good clarification. So any comments on this one or any concern about my suggestion that this is one area where we just need to create some parsimony because we've now said the same thing in I think three or four different places and we just need to get it into one so that we have a better shot at it being on the list that gets implemented; everybody comfortable with that?

**Cynthia Baur, PhD – Senior Advisor, Health Literacy, Office of Communications – Centers for Disease Control and Prevention**

Yeah, that makes sense. This is Cynthia.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay. All right, and then here is the 2018-2020 call to action, number 6, which is providers and technology developers should support the incorporation of PGHD in healthcare delivery which may include all these other things. So again I think we need to just combine that with the pieces that were on the last slide; it's almost like patient-generated health...this is the third location that PGHD shows up. It's almost like we throw it in...or it's thrown in as an example, sort of an and also aside in a lot of places.

So I think we're going to make the same comment and we're going to suggest that the pathway we described earlier is a little bit better; that in the short term we implement best practices, we get providers to do the PGHD piece in MU3 and we...and at medium term we have solved the standards problems with devices, that's what we're talking about here.

Oh, there's one other piece that I think is really important which is, Leslie talked a little bit about this earlier, too, when we said patient initiated health data. Even if it's patient...even if it's provider requested in the context of, I have a whole bunch of health information from minute clinic and my live help on line video visit that I did last week, plus my cardiologist's portal and I need to bring it to primary care, I think a really important thing is, and I'd like to do it in the next two years, but I'm just not sure that's realistic.

It would be really important to make it actually easy for providers to receive that data, upload it and be able to really filter through it so they can understand and act upon the stuff that's important. So how we make it easy for providers to work with PGDH or patient sourced data is, I think, really essential. I'd love to hear your comments and I want to ask you about the timeline for that. Thoughts?

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

One of the ways...this is Leslie, to make things easy is to help eliminate objections and the objections we often hear is, how do I know it's from the patient; so...confidence that they are who they say they are? Do I have confidence that this data is actionable and secure? So I think eliminating the technical barriers for patient initiated data will be important. And I know we're not supposed to talk about the standards, but things like identity, like being able to know that it's coming in a secure way, that it hasn't been tampered with by anybody else; so there's...maybe we want to encourage the development of standards and eliminate the technical barriers to accept patient-generated initiated data.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay Leslie, maybe what I'll do is say...is list those out, you know, by this time we're going to need to know, you know, by the 2018 window here we're going to need to know that the data's actually from the patient, it hasn't been tampered with, it's secure and it's actionable so standards need to be in place to support these objectives...

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

Perfect. Perfect.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Great. All right, good; we've got about 9 minutes so I know I'm going a little fast but, any other comments on this? All right, next slide. Okay, so this is the piece around in the 2018-2020 window again, technology developers deploying innovative aggregation platforms and tools so that patients can be that kind of curator or what...curator...or whatever, so they can play whatever role they want with managing their health information. So one of the comments is, look that actually needs to happen in the nearer term, if patients are going utilize Blue Button in the near term, the set and forget piece which we've mentioned before and then, I'm not sure what this bullet is because somebody made the comment about patient as power broker education, consents, no HIPAA lite. So any comments on any of that or anybody want to explain the power broker comment.

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

This is Leslie, I just wanted to make sure that we help the patients be powerful about their own data with digital health literacy and others, rather than say, boy we need a whole new set of regulations in HIPAA to support it. Because the patient is the only person with the ability to provide consent or...use of their information already, so let's help them understand that role rather than create another body of regulatory requirements; that was my thought.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay and does any...I mean, I don't think that we are...other folks were proposing the body, right, the new body of...I mean, I think there are some...unless you mean the privacy framework around what happens to my health information when its sitting in a PHR.

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

Yeah, that's what I mean and I don't want to take a lot of time on this, we can discuss this offline because I know you want to get to other things, but I think there's a...we need to have some philosophical discussion about how to make sure the patient is protected, but also that they understand their rights for use and the responsibilities that go along with that.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay, all right, that's helpful. I'll...maybe Chitra could make a note of that and we'll work that into...because I think we were making some comments earlier about, in the patient education space where I think that would be appropriate. And I think there's another one about understanding their rights and responsibilities with respect to privacy that's coming up shortly here. Okay, so any other comments on that? Okay.

So the next one is providers should welcome and use all information from other providers to avoid duplication of tests and ensure coordinated care. Yes, agree and I think we just talked about some of the tamper-proof stuff; but there is a comment about having that happen sooner, there's no reason it's not happening today and yet it's not happening today. So, I think we can...I think what I'd suggest here is that we look at the actions that lead up to this and if there's nothing there, we suggest this gets moved up and if there is, are things there we look at how we might build on this and make this one be a little bit more advanced. Does that work for folks?

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

Yes.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay. I'm just making notes here, okay. And then finally on this slide providers and developers give the majority of individuals and family caregivers the ability to contribute as much as needed to their electronic health information. So again it's on PGHD, so I think I'm going to...again, we've already talked about this like four times now, so we'll make...we'll create some parsimony and I'll use our discussion to create some comments here.

But by 2021-2024 either we've solved it or we haven't, I'm not sure what we want to see that far out in the future, but we'll give you a chance to kind of weigh in on that in the letter, because I do agree with the first comment here that says look, this is kind of like a goal, like what's the call to action? Right, what is it that we're doing? And I think that's probably right so we can suggest that this is either more specific or we might even suggest it's removed. Any comments on that? Okay, we'll figure something out on that because we know we all support patient-generated health data and we want to accelerate it; so, next slide.

All right, next slide. So we have privacy and security components in here; we might need to do this on the next call because we don't have a ton of time left, we only have about 4 minutes, in fact. I think I have enough that you guys have given me to give you some draft language to react to. What I want to raise though, very quickly because it does need a little discussion, is on the bottom part of this slide, which is the phrase behavioral health information and it's sort of coming out of nowhere and it feels like, at least someone commented that it feels like it's being given special treatment and why is that? Why shouldn't we be able to access our behavioral health information now?

**Clarke Ross, MA, DPA – Public Policy Director – American Association on Health and Disability**

Hi, this is Clarke; because there's a special federal law that protects behavioral health information, unlike all other forms. So that's the answer, whether you agree with protections or not that are in the law, there is a national law and this is a major issue in the behavioral health field. So that's the answer, no other area of health has a special law governing the exchange of information.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Right, I think Clarke my question is, that governs the exchange of information between providers, but this is about consumer access to behavioral health information, so does it change my right to access my own behavioral health information.

**Clarke Ross, MA, DPA – Public Policy Director – American Association on Health and Disability**

Yes it does because if a physician, a psychiatrist determines the information I share with you as the consumer could be...increase the risk of dangerousness to you or others, then I'm not going to share it. So, it's a whole minefield of delicate areas, but it's not just provider to provider, it's provider to the consumer.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay.

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

And it changes and it could be different in all states.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Yeah.

**Clarke Ross, MA, DPA – Public Policy Director – American Association on Health and Disability**

So there's a national law and then there are 50 variations, depending on whether states have taken the national law and either expanded or clarified.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay. All right, so I think we're going to need to talk about this on our next call then. What I'd like to suggest, we only have a couple of minutes left and we need to do public comment, if any of you have more thoughts or comments on the remaining slides, email them to Chitra and let's skip to slide, I think it's 28. We're going to ask you to turn your attention to section D and then...and send us back your thoughts on section D by Tuesday, March 17, so it's about a week from now.

And if you can go to the slide right before this, I just want to flag for you guys that the slide right before this has some suggestions about how we're going to think about how consumers get brought into section D a little bit more, but I want to ask you to also review section D from the perspective of providers; we are the Consumer Workgroup but they are asking us to review section D from a provider perspective as well. So, let's...I'm going to stop and ask Michelle to get the process started of opening for public comments and then I want to ask you guys if you have any closing thoughts or comments.

**Public Comment**

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**

Thanks Christine, Lonnie or Caitlin, can you please open the lines.

**Caitlin Chastain – Junior Project Manager – Altarum Institute**

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. If you are on the phone and would like to make a public comment, please press \*1 at this time.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

All right, so does anybody have any closing thoughts or comments that they want to raise? I know we didn't quite get through it today, but we did make a lot of really good progress. All right, so as I said, just go ahead and if you've got additional comments or questions about the remainder of the slides, send that in. In the meantime, while you're doing work on section D, Chitra and I will do an outline of comments on section C based on all of our work today as well as previous work and your comments. And then we will meet again to discuss D and we will figure out a process for how we're going to have time to discuss both section D and the draft comment letter; so, we'll work with Chitra and stay tuned on that.

All right, are there any public comments?

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**

No public comment.

**Christine Bechtel, MA – President – Bechtel Health Advisory Group**

Okay great. Thanks everybody, I know it was fast-paced, but I think we were very productive and we will talk to you again shortly.

**Multiple speakers**

Thank you, Christine.

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

Bye.

**Public Comment Received During the Meeting**

1. One issue with moving care planning into the next 2 years (2016-17) is that there are no standard defined for care planning. The next problem is that there are also no standards defined for the care team members. Having these standards defined and available must be a priority before these items in the electronic medical record can be seamlessly interoperable. Thank you.