



HIT Policy Committee Consumer Workgroup Final Transcript January 20, 2015

Presentation

Operator

All lines are now bridged with the public.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning everyone, this is Kimberly Wilson 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. Please also keep your line muted if you are not speaking. I will now take roll. Christine Bechtel?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Good morning.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Neil Calman?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

He's not on.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Here, thank you. Amy Berman? Clarke Ross?

Clarke Ross, DPA – Consortium for Citizens with Disabilities Workgroup, The National Quality Forum

Good morning.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. Dana Alexander?

Dana Alexander, MA, MSN, NP, BSN – Vice President Integrated Care Delivery & Chief Nursing Officer – Caradigm

Here; good morning.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. Erin Mackay?

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

Here.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning.

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

Good morning.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Ivor Horn?

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

Here.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning... Kim Schofield?

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

Here. Good morning.

Kimberly Wilson – Office of the National Coordinator

Good morning. Leslie Kelly Hall?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Here. Good morning.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. Luis Belen?

Luis Belen – Chief Executive Officer – National Health IT Collaborative for the Underserved

Here. Good morning.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. MaryAnne Sterling?

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

Here. Good morning.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. Nicholas Terry?

Nicolas P. Terry, LL.M. – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Here. Good morning.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. Philip Marshall?

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

I'm here. Good morning.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. Tripp Bradd? Wally Patawaran? Will Rice? Brad Hesse?

Bradford W. Hesse, PhD – Chief, Health Communication & Informatics Research Branch (HCIRB), National Cancer Institute – National Institute of Health

Here.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Cynthia Baur?

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

Here.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. Danielle Tarino?

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

Here.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. Teresa Zayas Caban?

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

I'm here.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Theresa Hancock? And Wendy Nilsen? 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

Here.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Good morning. And Gretchen Wyatt? Is there anyone else from ONC on the line? And Christine, I'll turn it over to you.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great thanks. And good morning and welcome everybody; we are going to continue our discussion today on the Federal Health IT Strategic Plan. We received comments from about 10 of you, so that's a great turnout, really good thinking and what we want to do today is go through the document section by section and make sure that you guys are comfortable with what's here and if you have additions or suggestions, we will take those during the call.

We also had a couple of you who I think had some epiphanies after the fact that we haven't talked about, so I want to make sure we talk about some of those concepts and decide whether they're going to stay in or out. But hopefully you guys have had a chance to review the document that was sent out yesterday, even though I know it was a federal holiday, and a big thank you to Chitra for all of her help and support in pulling this together as well.

So, I think our goal today is to be comfortable that what we are looking at on our screen as we edit it today will become the contents of first a presentation that I'll...hopefully Neil and I will make to the Health IT Policy Committee in February, which is our next meeting, February 10, I think it is. And then from there, once the Policy Committee accepts our recommendations or makes their suggestions, then that content will, and the content you're going to see on the screen today, will get turned into a transmittal letter that will come from the Policy Committee to Dr. DeSalvo, the National Coordinator. So, that's the process.

So we're going to dive in to that and then I also want to talk briefly, towards the end, about what is next on our plate, which is the Interoperability Roadmap and thinking about what you guys might need to get ready for doing comments on that piece of thinking as well. So, we're going to talk about that for a few minutes towards the end, but right now, any questions before we dive in? Okay. So let's go ahead and flip to the document itself, we can get folks at Altarum, I guess, are doing that? Chitra, do we have somebody who's making that switch over to the document or is it just me that I'm only still seeing the slides?

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

Um...

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

The document is up...

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

Yeah, it's up.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

...Just need to make it...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Oh, it is? I don't see it, does everybody see it or does anybody not see it?

Multiple speakers

Yes.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. So, why my screen still up, okay, let's try a refresh here. All right, so while my computer is doing whatever it's going to decide to do, I'm going to work off the real-time template. So you guys see that on the first page what we did was we just took some language that we'd already had further down in the template about what our charge is and how we are structured and what our sort of big picture thinking is and then we do some general comments.

So, the first...there's not a whole...there's one new thing in the overview section, and I'm...I know Phil is on the phone, and it's something that I want to take a few minutes and talk about. I have it in two places in this document, I think Phil started to talk a little bit about this on our last call, but we really haven't had a full discussion. I think it's an interesting concept so I want to see what you guys think about it and if there's strong agreement and alignment we'll keep it in and if it's...we'll just sort of see how that discussion goes. So it's in two places; one is where you see it highlighted in green and the other is more detail around it at the very end of this document. But we're going to just stick with the beginning, in the overview stuff.

I still, for some reason...I'm going to log out and log back in to the web, because I am not seeing the document, but I can see it on my screen. So, Phil can I ask you to talk about this proposed edit that you had suggested, particularly the green highlighted piece?

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

Yeah sure, sure thing. So it took me a long time to sort of formulate some language around this but, really what it does is just recognize the sort of transformation of the healthcare system away from visit and episode-based care and payment and incentives to more continuous and collaborative care and the role that health IT plays in that transformation. And so this particular statement here is just a high level supportive statement that introduces that in the introductory type of the document. So basically just supports shared care decisions that are collaborative and continuous. It's really elsewhere in the document that I had proposed that we include goals, objectives, strategies that are supportive of that.

But, basically the idea is that long term both quality measures and patient engagement as well as care planning and other ideas can be very supportive of transforming the healthcare system to one that really aligns the delivery system with the individual around shared care objectives and again, just really recognizing that transformation to care that's more continuous and collaborative. So that's just introduced here and...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

I have a question...

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

...I do apologize that I didn't get it in on Friday; it took me all weekend to formulate it, so.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Thanks, so I heard a question?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Hi Christine, it's Leslie. I just would like to talk about shared decision making, not just care objectives because care objectives is...might be considered episodic; I think it's this tactic under what you just articulated earlier which is more of a shared decision making framework that's collaborative, so people can get access to care they need and say no to unnecessary care rather than just my objectives of my care. My objective might be I don't want that; so, shared decision making lets people say no, too.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, I think...so I think what I'm hearing...the reason I wanted to raise this is because what I'm hearing Phil describe is kind of an umbrella for a number of the areas that we have said as a workgroup we support and...or we have edits to, but fundamentally support. Shared decision making is definitely one of them, so is the idea of person-centered care planning as well and patient-generated health data.

So, part of what I think is interesting about what Phil is suggesting is that the idea of a shared...focusing a strategy on shared care objectives at a broad level could have a number of strategies underneath it including shared decision making, care planning and PGHD. I think Phil even mentioned quality measurement, certainly patient experience but to me it's interesting because it represents a cultural shift toward that partnership component that we are talking about in the second and third areas of our charge, which is the partnership between care providers and even community-based organizations and others and patients and families in support of both health and care and then that partnership in actually healthcare transformation.

And so having this idea of shared objectives, I feel...I just thought was very interesting because so many things would fall underneath it. Phil, am I representing your idea correctly?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yeah.

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

Yeah, you are representing the idea correctly and I would like to respond to the comment earlier from Leslie that is that decision making is a broader idea. I actually, at least the way I think about it, it's actually a narrower idea because it really takes first the delivery system and the individual to be on the same page about what they want to get out of their care; and that's really what this is saying. And then under that, you're making decisions that are shared decision making that are in support of those care objectives. So...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

And I...the reason I just pushed back on it a little is that most of the time when the "no" happens, when people say, no, I don't want to do it. It's not when they're discussing their objectives, its prior to that that says, you know, hey the evidence says this but my values say that and so really I'm not going to get that referral; I'm not going to go on to the next step. So if under here you also include the idea that people could say no, we're not even going there, I'm okay with it. But I think that there is a lot of unnecessary care that if a patient were given enough information of evidence and their values are considered, they might not choose it.

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

Sure, yeah, agree.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Christine, Nick Terry. So as I hear your articulation, Christine, yours is the broader...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

...umbrella point, isn't it?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yes.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

And I endorse that as well as this edit.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So perhaps...

Dana Alexander, MA, MSN, NP, BSN – Vice President Integrated Care Delivery & Chief Nursing Officer – Caradigm

So this is Dana Alexander. I would also concur that I think if we determine or decide that the care objective is a broader definition, it's just then important that somewhere in this document then to define what we mean by that, to include in shared decision making and whatever else that we include here in the broader definition of a care objective. So, I mean one way to handle an option would be to add shared care objectives and shared...and decision making or again, to define a broader definition somewhere in the document.

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

Yeah, this is Ivor. I would agree with that because it's n...I mean, for someone who doesn't use that language commonly, it's not clear what exactly you mean when you say shared care objectives. So we need to be, I think, a bit more specific in providing clarity of definition when we use these multiple terms.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So let me do this, let me ask the folks at Altarum to scroll down to like the second to the last page, below the table. And for those of you who have the document live, you can do the same thing. So keep going, okay. Can...folks can see where it says this new goal, and maybe Altarum, can you guys edit the document to just push that down onto the next page because there's more on that page that I want the group to take a look at. Thanks.

So we don't have to agree on all of the wording, we don't need to necessarily wordsmith but I think conceptually if we can see if there is alignment around this idea then I can recraft it. But what I'm wondering is, on the goal, if what we're really talking about is building a culture of shared health and healthcare objectives or health and care objectives, right? So that's really around when I'm listening to Leslie, the broader frame of, what do I want for my health and my quality of life first. And then how does my care align to that; I think that's the concept that we need to have a broader frame.

We might say build a culture of shared health and care objectives, so that would be one suggestion. And I think there's a piece in the bullet that starts with description that I'll just highlight, which is...so health IT playing a crucial role in supporting care delivery systems and individuals coming together around shared objectives or goals for their care, so we might say health and care; and aligning patient engagement efforts around those objectives. So...and I would just suggest that we not...that we m...if we want to suggest either a new goal or objective to ONC, we need to do that at a broad frame and give them some suggestions for the things that might come underneath it like care planning and shared decision making and some other areas; but let them do the wordsmithing and take the concept and make it operational. So, does that clarify some things?

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Um hmm.

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

Christine, this is Erin; I really like all of the language that's been added here and I love the ideas behind it. I'm just wondering, and I don't know, perhaps this language came from Phil so maybe he can fill me in but, is there a difference in people's minds between suggesting the addition of a new goal and, in my mind I see the alternative as sort of folding all of these ideas under a new objective for "C" as opposed to new goal "X." To me it seems to...

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

This is...

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

...yeah, sorry, go ahead Phil.

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

Yeah, yeah, so, well, as I read through the document and I saw that graphic, you guys saw that graphic that was sort of that cascade and then it had the goals down in the lower section?

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

Uh huh.

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

You know, it just struck me that it just continues to perpetuate this sort of two-sided approach; one delivery system, other patient. And at least what I've observed, and perhaps you all have as well, is that there's really an opportunity for something that sits between and really bridges both of those. And so that's why I suggested it as a new goal because when you have providers and individuals coming together around shared goals for care, and those are documented, measured, it really isn't just patient facing and it's not just delivery system facing. And so that's why I suggested it as a new goal kind of sitting in between, but I know introducing a goal is kind of a big, bold idea here. So, there's also some practicality to it, I'm sure.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie again. I think that...I think we're headed in the right direction, my only other concern that I...and maybe is addressed someplace else, was in the whole idea of sharing, talk about care delivery and individuals and we leave out community and we leave out patient support community. So when ONC or when the federal plan talks about community here, they're really talking about public health ...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

...they're talking about other things. But the whole patient support network is completely left out of this document. And it will be very important as more of care moves into the home and more telemedicine is used and telehealth; so, I'm not sure where we put that, but the patient support community needs to be in here.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah and Leslie, I agree with you and we got similar comments from a couple of different folks. So as we go through the document, you'll see it...you'll see that we're making some requests of clarifications on that point and some of the other areas. But I hear you with respect to this as well, which is more the community-based organizations than public health stuff.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Right.

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

So, this is Cynthia. So I actually see that this language introduces, at least for me, some confusion. Because I had made a lot of comments about the multiple uses of person-centered care in the document; I think I counted about 12 uses in the draft that we reviewed. And for me the notion of person-centered care would need some work to align with this notion of either shared objectives or shared decision making. Because I'm not for me they can kind of sit side-by-side as proposed without some additional explanation and linkages, because I was confused when I read the proposed new goal because neither the goal statement nor the objective statement referenced anything about health IT.

So, I mean that for me was sort of another aspect of just not really being clear about what was proposed. So there are two things; how do you link a notion of person-centered care or is that concept going to disappear from the document not and be replaced by this notion of shared and negotiated and collaborative decision making. And would the goal need to be redefined...goals and objectives, if they go forward, need to be refined so they specifically reference the linkage to HIT?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So I want to make sure, Dana, I understand your first comment about person-centered care. Are you saying that to you, person-centered care is different than a collaborative model because, why? Person-centered care means I make the decisions or what is...where's the disconnect for you?

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

Yeah, so this is Cynthia.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Oh, sorry, I thought it was...

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

So the link in the paper now is to ONCs person-centered care materials and white paper and whatnot and so in their paper, they say the power of each individual is developed and unleashed to be active in managing their health and partnering in their healthcare enabled by information and technology.

I think it leaves open the door to some of the things that Leslie was talking about, to basically saying, well, I don't really want to negotiate that with you, I want to just say no and kind of go a different direction. Whereas for me sort of this notion that Phil was laying out, and maybe you, too was that there would be this constant collaboration until we get to the point where there is consensus and agreement and I'm just not sure that I think that's how things will always turn out.

So for me there is a bit of a tension between a person-centered care idea as it's laid out in the current ONC documents and the language and the discussion we just had around this notion of shared and...approaches.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay, thanks, that's a helpful clarification. Other comments, thoughts, reactions?

W

So I...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Go ahead. I think somebody was just trying to make a comment.

Nicolas P. Terry, LL.M. – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

This is Nick, it wasn't me but I will jump in.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay.

Nicolas P. Terry, LL.M. – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

It's a wordsmithing issue rather than anything, and maybe when Chitra or someone does one of their great sweeps through the document; this goal, which as I said I think is a good idea, uses the word individual. Elsewhere we use consumer, patient, family, physician, provider; having some sort of consistent language or at least great care as to the language we use in any particular section I think would improve the document.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay, thank you.

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

This is Clarke Ross. I can send you all language that the National Quality Forum uses; they use person, but then they basically say in different context, people are called different things and it's appropriate in different contexts, and the overarching word is person. But recognizing that some people want to be called consumers, some are patients, etcetera, etcetera; maybe that's the way out of this is to cite the National Quality Forum, a brief paragraph on terminology.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Clarke, go ahead and send that on to me...it's Christine, if you can and I can work with that.

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

Okay, I'll do that while the call is going on.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Thank you. Okay, other thoughts?

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

This is Clarke again; I have a thought on the larger point in the general comments; is this a time to do that?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Umm, let me try to wrap up the culture of shared care objective conversation and then we'll go to you, Clarke. Does that sound okay?

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

Yup.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. So what I'm hearing is agreement about the concept of shared objectives, but less agreement in how specifically that might be reflected here; whether it's a new goal or not or an objective or, there are some potential tension points and things like that. So I think what it sounds like to me, unless somebody wants to challenge me, is that there's not quite enough agreement for how to do that and include some of our components underneath is as a goal or an objective, but there is agreement around the concept. So what I can do is go through the document and find some of the right places and perhaps it's at the big picture level on the first page where we can say, we're also very interested in finding ways that we can shift the culture of healthcare to be oriented around shared person-centered objectives so that we're really again, talking about supporting that partnership between clinician, patient supports and the patients and families. Does that sound fair to folks?

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

Yeah Christine, it's Phil. I think that sounds good to me. And separately I'd love to get folks thoughts about this broader idea that really long term the quality measures that we measure in the healthcare system and what we engage patients around can come together. They can consolidate around those things which both patient's value and the delivery system can help them to achieve. And so in my mind at least, it does represent a bit of a tidal shift, I think an important one, but I appreciate the consideration here today.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Christine, this is Nick. I would certainly continue to endorse the strong new overarching goal. I think once we see very general language coming from you at the top of that, I think the other pieces will probably be able to be fitted in quite nicely. I think it's also a real opportunity for us to give ONC an indeed broader, and to HHS, a real sort of conceptual place where things like patient-centered care, personalized medicine, even population health research, where that can all fit comfortably together.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

And indeed also things like the emerging wearable and mHealth technologies where so much of health is going to be pulled by consumers rather than being pushed by providers. So, the opportunity here, I think, is a very great one to give us an overarching concept.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So Nick you're saying that you actually think it's...that what Phil was describing around having a new goal where other things could fit that is around shared objectives and care, that was should pursue that?

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

I think so.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

I understand why some of the wording at the moment might not fit with some other folks thoughts, but I think a...if we can get the language to be broad enough, I think other people will see how their stuff fits in, or I hope that's the case.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah. So I...I mean, I think you're right; my concern is time because we didn't have this conversation on the last couple of calls. We don't have a whole lot of time here; we have to turn this around in two days so we don't have another call to talk about this. So do folks, I'm particularly curious to hear from people who had some concerns or comments about the specifics of this concept. Do we want to spend some time, or I could try and create a framing of either a goal or an objective, or whatever this concept is and go back and forth on the language offline or via email within the next 24 hours? Are folks comfortable doing that or is it a better plan for me to try to build the concept in in some places but not try to revise the structure of the Strategic Plan as much as to try to really highlight that concept in the right areas?

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

This is Ivor. I mean I would align with doing the second; I think it's more practical, especially given the timeframe that we have. I, along with everyone else agree with the concept as a whole, but aligning it with the current structure seems more useful to me in the long run, and more likely to lead to incorporation.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Other folks want to weigh in as well? Thank you.

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

This is Erin, I totally see where Ivor's coming from and I'm tempted to say, too, pepper in or sprinkle in these ideas elsewhere but I think ONC already tried to do that with its multiple references to person-centered care planning, with it's sort of random references to social determinants of health and sort of other issues of importance to consumers.

And I'm wondering if sort of given the fact that there were these sort of phrases or hot topics sprinkled throughout, but still everybody was so confused and it didn't give us what we working for, if it's worth it to spend some more time and flesh out this idea. I personally would recommend moving it forward as an objective for "C" as opposed to a new goal; I think that's less likely to disrupt the overall structure of the plan, although perhaps other folks on this call have an idea about that. So, I don't want to throw a wrench into things, but I personally would be in favor of trying to move this forward as separate object...or outcomes and strategies.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Thanks Erin, that's helpful and I think Erin did really nice framing in saying, I think that part of the problem is, and what Phil picked up on, is that these things were sprinkled throughout, but they're not really coming through in a resonant way. So that's a good framing. Other folks want to weigh in on this?

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

Christine, this is MaryAnne and I'm wondering, as I'm listening to this great discussion, if it will resonate with folks moving forward if it is not pulled out into a separate goal. Obviously the sprinkling method didn't work for us, probably isn't going to work for the consumer, so unless we are bold and pull this type of rich material out into a separate goal, I wonder if these important concepts continue to kind of get lost.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Thanks MaryAnne, good comments. Anybody else want to weigh in? So far we're leaning on the side of being bold.

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

Well, it's Phil again; you all know where I stand but I would just say that this is a vision paper. This isn't something that dictates what we do in 12 months; there are 6-year objectives here and so I say now is the time to introduce bold ideas because it's a vision paper.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yup, thank you.

Dana Alexander, MA, MSN, NP, BSN – Vice President Integrated Care Delivery & Chief Nursing Officer – Caradigm

This is Dana Alexander and I would also support a new goal. Again, thinking that this is a way for us to put this forward as a bold idea in a very clear and concise way and then if ONC makes the decision that it's too disruptive to their framework, in terms of how things are set up, then they could make the choice to incorporate the concepts accordingly. But I think in order to project our viewpoint and how we feel about this is to again, to put it forth as a new goal.

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

This is Ivor; since I seem to be the minority and the naysayer in the bunch, but not really because I agree with what you're saying. My concern, and I'll play devil's advocate here because I really am in that role because it's not that I disagree with anything that everyone's saying, is that if we put it on just as a separate goal and leave it as a separate goal without giving them guidance in how to incorporate it.

Because I think what they're looking for is guid...you know, yes, we wanted to make a bold statement and whether we make it as a separate goal or put it in the letter to say, this is missing and this really needs to be here and then say, and this is how we...you can incorporate it into these other things. I think the fact that they put it in and sprinkled it in a little bit is saying to us and from them, we don't really know how to incorporate this into all of these things and we really do want to.

And I think that's what they're asking us and to put it as just a separate objective without giving them some idea of how they incorporate it in those areas in a much more clear and structured way, I think is going to leave it hard for them because they've got this separate objective but they still don't have any understanding of like, well how do we put it into all of those places? And I think any way that we can provide them with guidance in how to do that I think will be helpful instead of sort of making a statement but not sort of giving them some direction because I think they really are looking for it.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

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

I think they get it and that’s why they’re saying it a little bit, but they’re like, but we don’t know how.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, okay. So here’s what I’m going to do. Since folks are leaning toward being goal, but you are raising a very important point which is, we need to be practical and we need to be helpful, and I agree. And as the one who is going to work with Chitra to try to get something that resonates with everybody on the call, I can tell you, I’m worried about it.

So I hear the point; what I’d like to do at this point is I think I’ve got enough from you guys to go on and as we go through the rest of the comments that we are planning to make, we will highlight some areas that...where we will give guidance as to what comes underneath this bolder goal. Phil’s done that, in fact, he’s gone so far as to create 3 and 6-year outcomes as well.

I think maybe what we would do is talk a little more generally, because I don’t think we have time to get complete agreement on outcomes and strategies at a granular level in this group. If we had one more call, I would say we would do that. But I think we can give enough detail as to say, listen, this is where your strategies such as, person-centered planning and shared decision making and alignment between quality measurement and patient and family engagement need to come together.

So we’re about to go through the specific comments in this document and we will flag those areas that we might point to coming underneath this bigger picture goal, as we go along. Does that sound good or does anybody have a better idea?

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

Christine, this is Chitra; I also want to just emphasize that this is a federal plan, so it really it’s what the federal government can do in terms of programs, regulations and grants. So, just to keep that in mind as you discuss this.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yup. That’s a great point, yup. I think part of what we’re talking about though is taking the stuff that’s already been proposed by the federal government and aligning it, but under an explicit concept of that partnership between the care team, patients, families, community and other patient supports. But, it’s a very important reminder. All right, so let’s go ahead and keep moving; unless anybody has a burning comment on this. So, any burning comments before we keep moving?

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

This is Clarke...

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

This is Amy Berman...

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

...you were going to let me comment on the overall overview sentence.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, that's where I'm going to go right to next, Clarke, but Amy, was your comment on this concept?

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

Yes. Just one small comment and that would be on the value of across providers being able to understand a shared goal, which is one nuance that I don't think that we've raised yet.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

And that's one of those safety, preventable harm kinds of issues that if they are essentially trying to achieve the same kind of goal, that they're not working against each other.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, I think I have assumed that and we've assumed that, so if we need to point out more specifically when we get under the...I think mostly that fits under the care planning piece, because it's person-oriented, then let's raise that at that point. Clarke?

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

Thank you. We currently have in the proposed edit; it strengthens the delivery of healthcare and long term services and supports. I would like to add comma, including behavioral health. I've sprinkled behavioral health in some green comments through the document.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yup.

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

But the reason to put it here, shared with Christine and Erin, the mental health liaison group has a draft letter on the strategic plan and the letter sort of assumes on behalf of the mental health and behavioral health fields that ONC either doesn't care or doesn't get behavioral health. And having it right here in the first sentence would be very helpful to send that message that we do care and we do get it and there are some challenges.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. I'm going to include that Clarke as a separate bullet unless anybody has any objection. I mean, I just put a new bullet right after it that suggests that they're clear that it...long term services and supports, etcetera include behavioral health. Okay. Any other...so, I don't think anything else is new and again, I'm assuming you guys have had a chance at least to scan this document. So I want to focus only on things like Clarke is raising where you've got either an edit or an addition that you want to propose. As I said, we got comments from about 10 of you and we did our best to find all of the areas of alignment and reflect as many comments as we possibly could in here.

So, on the section...so are we...sorry. Let's go back up to the top for folks at Altarum, page 1 here. Okay, so you see the strategy...strategic goals and objectives. So we already have discussed the comment on the collect, share and use framework. Anything else in this section? Okay, great. So let's get to page two here. We had a couple of things that were added under federal health IT principles and they were around using health IT to improve patient family experience of care, some additional detail around the equity principle and the first bullet that you see here around consumer empowerment was something that we've talked about and you've seen before. So, any comments on this section of the document, that's principles or update section?

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

This is Amy, I have one comment and that is, that this may be one of those additional sprinkling areas that while the last bullet says using health IT to improve patient and family experience of care, it actually can improve the likelihood that they're getting care that matches with their goals and values, which is more fundamental than even the other three bullets.

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

Christine, this is Cynthia. So I was wondering, because there was a lot of discussion on the prior call about the principle respect individual preferences, and that's also a place where person-centered care comes up and there was some discussion about the alignment of all that; so I'm just wondering how the comments here would be directing ONC staff. Would it be to...would these comments be directing them to add additional principles and leave the respect individual preferences in place? Because I think that might not be clear about should...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Uh huh.

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

...should that principle stay as is and these are additions, because I'm not sure that that was...I think there was a lot of confusion on the prior call about that, the respect individual preferences principle.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, so how I've envisioned it is that we're simply saying these...this is what's missing. We're not giving ONC the context of we were wondering if it's in this principle or that principle. So I think we're not...we're silent on everything else except to say, these concepts are missing and how they want to edit is up to them. If people feel like they want to say, we particularly support the respect individual preferences bullet, that's fine but I think what we're saying is, and we can frame it up more broadly in the introduction to the section we can say, great set of principles and here's what's missing. That would be the approach that I'm going to propose, which is, great set of principles, here's what's missing but we're not really going to take on the content. Does anybody want to suggest a different approach?

Nicolas P. Terry, LL.M. – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Christine, it's Nick; the only small suggestion I would have is really they have sort of buried access a bit here, it's the final piece in the focus on values section. And I think that our concept of information technology in healthcare going forward is one that has the potential to drive access, improve access as well as the other metrics; just a thought.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, so Nick, I think we've put that in a more meaningful place in the document, which is gosh, at least I meant to...you know what, I may have called it...yeah, telemedicine but I think I meant to call it access. I would...

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Uh huh.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

...suggest that we...I'm not going to...I wouldn't worry as much the principles at this point as I would about really the strategies, the objectives, which is the meat...where the actual federal actions will be catalyzed around. So, let's make sure that access comes through in the detailed section, does that sound okay?

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

That's perfect, thank you.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

All right, so let's...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Christine...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

...I'm sorry, this is Leslie. I just, along with that access, access to care that's needed and the ability to say no to unnecessary care. I just...I'm not sure where we get that in, but having the right information for people to make good decisions is important and the actual research shows that people make more conservative decisions, they actually can get different approaches to care, so, I don't know where we get "no" in there somewhere, but I'd sure like to get it.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So Leslie, there is a section on capacity for shared decision making, so when we get to that point, if you have an edit beyond what's there, then let's talk at that point. Does that sound good?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Oh...that sounds fine.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay, it's on page 5 so you can flip ahead if you'd like to. Okay, so let's dig into the details, unless anybody else has a burning comment on this section. We've got about 40 minutes to get through really the meat of the document. What...so, you...this is not new to you guys, what we've simply done is, we took everything we talked about on our very first two workgroup calls we built the framework around our workgroup charge. You guys have now discussed and seen draft comments and so now what you're getting is a revision.

So, these are the same areas, there's only one that I'm highlighting as something we need to decide whether or not we want to keep in, because nobody seemed to be particularly enthused about it in the comments that we did receive. So, what...I'm trying to think about the best way to structure this, I want to maybe take this first section, which is about engaging patients and families in their own health and healthcare and think about the content here and just make sure, I'm hoping again that you guys have read this, that you're comfortable with what we've done. And I'll try to summarize some of the expansions. Is that...does anybody want to suggest a different approach?

W

Sounds good.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay, good. All right, so the first area is ability for consumers to aggregate data from different sources. So a number of you guys...the changes here, it's fundamentally the same thing, it's just that a couple of you guys really gave some concrete examples of why this was important; things like too many portals, too many passwords is going to affect consumer engagement period, you know, getting care outside the care team. So mostly the work that we did here was to just clarify and give some specific examples to help people understand why this was important to really think about.

So, I'll just kind of give you guys some time to, in between my expl...I'm just going to explain in each area what's changed, if anything. And then if you guys...I'll just pause in between and if you want to weigh in on something, weigh in on it at that point. So I'll pause now and take any comments or questions. Okay.

So, the second area is portal usability and design. So this is an area where again not much has changed but we talked about the fact that this needs to be...the new addition here is this shouldn't just be like in Goal 4, right? Where it would be obvious, but it should be in Goal 1, which is about increasing adoption and in Goal 3 around improving access and experience. And we tried to make those connections to show ONC that it touches all these goals and it's a huge strategy so portal usability and design.

So we need to really consider that. So there's nothing new here, but we did also include some of you guys' comments around how to incentivize user centered design, participatory research and potentially exploring certification for consumer facing health IT, which I used that broad "consumer-facing health IT language because I'm a little bit concerned that we're focusing on a platform here which is portal usability and design.

But we don't want know exactly where the field is going to go so one, when we first started to think about the idea of Blue Button, it was because we weren't really sure if portals were going to be the wave of the future because you might have too many portals and blah, blah, blah. So what if it's PHRs or what if it's something, you know, an App, a mobile App or something that we haven't really figured out yet? So, I tried to be a little bit broad, but the first section does focus on portals specifically. So any thoughts on that? Okay.

So we'll just keep moving. And I'm just going to leave things as is unless folks have comments. I think it does reflect where the field is at now, but not necessarily where it may or may not be going; we don't know. So the next section is access to health information through mobile devices. We had made a comment earlier that they need to define mHealth; we're glad it's in here but you guys need to define it. And this is just really clarifying that it should be in the plan in these different elements.

So this one did not change too much, except to bring in some of the other concepts we've already talked about which is don't think just about mobile access, think about how you can contribute, share and manage on mobile platforms, not just access. So, comments on that?

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Christine, this is Nick. Just one point, the final sentence, we're glad to see the emphasis on mHealth security. I know we talk about privacy later, but adding in some expectation of increased privacy protection in this specific context might not be a terrible idea.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Why don't I just add a sentence that says, see our comments in the privacy section on this topic.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Thank you.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. Because you are right and you...Nick, you sent a lot of great comments and your sort of framework of the three levels of regulation was really good; I just...and it was like really instructive to me. I just wasn't sure how we could bake that in so I tried to do that conceptually, and you'll see that when we get to the privacy piece.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Oh, I'm very happy; don't worry.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

I was probably getting too teachy.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

But it was helpful, I mean, it was great so I appreciate it. Okay, so the next is, digital divide at the consumer level; so really this is not one that changed a ton but I did make some clarifications around creating outcomes that focus on equity and strategies that help address health disparities, which is really what we talked about.

And along with mobile devices and broadband, the strategic plan should incentivize community health practitioners and local leadership to think about other forms of access like public space computers...I think Cynthia, that might have been one of your comments; but I thought that was great so I've incorporated that here. Any comments? Okay, good. Moving right along...

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

Umm, this is Amy...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

This is Amy Berman, I've got one question. Because I haven't been on this committee nearly as long as the rest of you, forgive me for asking but in that last section, I don't see anything about a person's goals also reflected there and I'm wondering whether it's possible that we could do everything to support somebody knowing what somebody is doing to them, but not necessarily helping them understand what they should do for us?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Amy, tell me where you are when you say the last section.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

The one looking at addressing the digital divide at consumer level...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Ah ha.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

...and specifically, I'm looking at the focus on equity and I'm wondering if it's a focus on patient-centeredness equity and strategies that help address health disparities. But the patient-centeredness is noticeably absent to me on this one.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So let's, if...that is something that we tried to put in in a number of other places that's in the next section.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

Okay.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

This is really focused on if we make all this health information available electronically, but I don't have a smartphone and I don't have broadband and I can't access...it's like it's really about access and the technical infrastructure.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

...okay.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Then we're going to create much greater disparities in care. So it's really about access, but I think if you bear with me and get into the section that's around that partnership, you can...you'll see that those concepts are reflected and you can probably find ways to strengthen that.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

Thank you for your patience.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, no, no problem. Okay, so the next piece is on health literacy and clear communications. We had a lot of discussion around this; it actually shows up in a couple of different places in the plan, although again, it's kind of that sprinkle approach and so it was hard to track down and see everything kind of coming together. But what we did is that strongly support Objective 1B, Strategy 3 and 3A Strategy 6; those are about health literacy.

But we also said you guys need to have outcomes related to improving health literacy because at the end of the day, we need to measure whether we're actually improving at the 3 and 6-year mark. We also suggested data health literacy be included in Objective 3A and said that it's an important part of usability and safety and 1B. So, we're kind of trying...and then, of course, a new Strategy under 4A, where we tried to focus on education for consumers on health IT literacy.

So, and then I have a note about leveraging ONC and CMS relationships with providers, which you guys will get a second, because we talked about that somewhere else. But nonetheless, we're kind of still on the sprinkle approach, but we're at least trying to, you know, this is more than a sprinkle and it was the best, I think, we could do in their framework; so comments and thoughts on this piece.

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

This is Ivor; I mean I think it's great in...I mean, this is something that I've been...I wasn't able to be on the last call but has been one of the most important factors for me is this clear understanding, particularly as it relates to underserved populations and less educated communities that they understand what they're getting into because we're providing them with all these resources and if they don't have the capacity to truly partner because they don't have health literacy, then it's kind of a...and the digital divide becomes the second scary factor.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Right. So are you comfortable with the way this is written or Ivor are you suggesting a change.

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

Yeah, I'm comfortable with it; I just wanted to compliment you guys on this strong work and a strong language.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Oh great, okay, thank you.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Me too; this is Leslie. I think that stating where this all applies throughout the document is really good.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great.

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

And this is Cynthia, I agree with all of that.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yay. Okay, good. Happy day, let's move on. All right, so the second section is enabling partnerships, and I sort of...I actually took...we had our...because in our charge we talk about partnerships, consumer provider partnerships. But actually, this section became far more about partnerships beyond the care team as well, so, I kind of generalized that a little bit. So the first area that we have, and this is...we didn't really put this in any particular order, so, Chitra, we should probably note that we're not commenting in order of importance here, by the way so people know that up front.

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

Okay.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay, so the first area is patient-generated health data, we've had a lot of discussion about this and there's not a whole lot that's new here, but similar to what we did under health literacy, I think it was Erin Mackay had suggested some really great ways to think about how patient-generated health data supports other parts of the strategic plan, and is therefore really important. And so I went ahead and stole that, pretty much verbatim, Erin, so good work there, and talked about all the ways that it's important. So again, we're trying to shift it earlier, given that we've done a whole bunch of work around patient-generated health data, shift it earlier in the outcomes arena and then show them all the places where it's important. Comments.

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

Christine, this is Clarke Ross.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Um hmm.

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

Christine and I had an email discussion, I'd like to see this whole section address the potential use of the CAHPS Survey, Consumer Assessment of Healthcare Providers and Systems Survey, recognizing that it's inadequate and incomplete at the moment and there are multiple CAHPS Surveys. CMS and AHRQ are working on one for home and community based services for persons with disabilities who are aged.

But, this is a standard consumer survey that health plans are held accountable for and it's an evolving, evergreen kind of process, so I'm not defending the current survey instruments. But all of these topics, person-centered planning, shared decision making, and patient-generated data even the communication one prior. One approach would be to build a CAHPS Survey instrument or reference it here with a notation that it has to be significantly...the instruments have to be significantly enhanced. So, that's my suggestion is some kind of reference to an enhanced CAHPS Survey to partially document our success and status with these various important issues.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So Clarke...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie...oh, I'm sorry, I would just echo that and it's not just CAHPS but patient reported outcome measures or comparative effectiveness all would incorporate patient-generated health data.

W

This is...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So let me...hold on, let me make a clarification before we get too far down this path because I need guidance from you guys on where and how to incorporate this, depending on what you're trying to do. So when I think of patient-generated health data, it is not necessarily like a quality measure on experience of care, it is more around like health data, so data coming from me that's going to inform my treatment. Whereas CAHPS is more of an evaluative tool and Clarke, I think I heard you say how we're going to inform our status and our progress, etcetera.

So, let me point out one thing, and then I'll pose the question. What I did, and I forgot, I skipped over it is on the second page, under the section called strategic plan development and update, I included a bullet that said, we understand that the strategic plan will be further updated with measures that indicate progress towards the outcomes. We fully support that effort and we urge to involve consumers in developing or selecting measures. We also hope that those measures will include measures of consumer, patient and caregiver experience with health IT systems and tools.

I put that there because to me, patient, caregiver experience is a broader evaluation methodology that could evaluate a lot of different things and should evaluate the use of health IT in different ways. But I didn't put it in the specific areas, because I think it's too easy to say, well that's not PGHD or that doesn't belong here, but it's really an overarching frame. So that's how I approached it and Clarke, tell me what you're looking maybe to do a little bit and where you see that fit.

Gretchen Wyatt, MA – Policy Analyst, Office of Policy & Planning – Office of the National Coordinator for Health Information Technology

Christine, this is Gretchen Wyatt from ONC. To this point, before we have Clarke speaks about this...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Sure.

Gretchen Wyatt, MA – Policy Analyst, Office of Policy & Planning – Office of the National Coordinator for Health Information Technology

...if I could reiterate the fact that when we say that we will be incorporating measures, it's measures on the federal governments progress towards these goals.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Ah.

Gretchen Wyatt, MA – Policy Analyst, Office of Policy & Planning – Office of the National Coordinator for Health Information Technology

So it's more of a...each individual program would be looking at how effective is the CAHPS Survey, do we need to modify it? How effective is the uptake of patient-centered generated data into various programs? But, it's...the metrics that will be selected are on our ability to actually accomplish these goals.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. Okay, so let me...all right, thanks Gretchen. So I need to change that. So I think Clarke, maybe what you're saying is, the federal role her, based on what Gretchen has just said, might be something more like a strategy that measures consumers experience with health IT and that might be implemented through PCMH or ACOs or other things, does that make sense?

Gretchen Wyatt, MA – Policy Analyst, Office of Policy & Planning – Office of the National Coordinator for Health Information Technology

Yes, absolutely.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Clarke?

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

Yes, I'm trying to take a standard survey instrument that all health plans in America use and...but I recognize it's not adequate, and build it into these various dimensions. And there is a health data generated...patient generated element in a CAHPS pilot for people with intellectual disability and mental illness. For example, their experience with side effects of medications; but it applies to multiple elements in this section.

And I don't care where it is, how it's stated, but I think we have this, and my whole thing with the National Quality Forum and CMS later, we have these federal initiatives going on so we want to strengthen our argument by referencing these other initiatives. And CAHPS is just one way of doing that.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

But Clarke, are you trying to...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

...measure patient...Leslie, hang on one second, I just want to get a clarification from Clarke. Are you trying to measure patient experience period, in different aspects or are you trying to measure patient experience with health IT, which is going to be portals and things like that?

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

I'm trying to include in the broadest patient experience way the health IT agenda and elements.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. Leslie, go ahead.

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

And that health IT should be integrated and incorporated into these larger initiatives such as documenting the consumer experience.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

And I would just agree that the patient-generated health data is about...the CAHPS Survey is not just, how did you like your care? It's much more in depth. I agree, it's not totally complete, but I think a very practical approach is questionnaires of any kind that are going for patient-generated health data...sorry about that background noise.

And so, I do believe that the patient-generated health data should incorporate survey instruments, patient reported outcome measure instruments and comparative effectiveness instruments. They will change how healthcare is delivered not only overall for a population, but for that particular patient. And so, I think it's just too narrow to think of patient-generated health data only in episodes of care. If we're going to get to a learning health system, it has to be...there has to be no discrimination on what kind of data can be incorporated, that the patient wants to be incorporated in their record.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay, so I think what I'm inclined to do after listening to you guys is, I think the best way to reflect that is to suggest that ONC and CMS use their outreach and education efforts with providers to also promote patient experience measurement as one form of patient-generated health data. That close?

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

I'm good with that.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

That helps.

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

Um...it's Phil; I lead product...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

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

...management and product strategy at Press Ganey for a few years so I'm familiar with the area. You know, patient-generated health data is just such a new area that really more on the clinical side, helps the delivery systems stay in touch with patients; and CAHPS is so not clinical, it's experiential. And it's, I don't know, in my mind it just so mixes apples and oranges. If you try to introduce CAHPS into the whole health IT infrastructure and...EMRs and all that, it's really a fish out of water, I think, in my head.

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

This is Clarke. We're introducing the consumer experience in every Health & Human Service funded activity in this nation through CMS, Medicaid, Medicare and the National Quality Forum. So to argue what we're trying to do electronically should be exempt from what we're doing in the trend, someone earlier said this is a 6-year plan. The consumer experience is fundamental to clinical decision making.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, so Clarke, let me...I totally am with you, but I'm also...I completely understand what Phil's saying. I need to find a way to straddle. What I think...part of what...we struggled with this and Leslie will remember this because we were both on the Patient & Family Engagement subgroup in Meaningful Use. We struggled because we really looked for a way to connect EHRs to patient experience, but the problem is that it naturally walks down a path of baking patient experience answers at a granular level into an EHR platform which is completely inappropriate from a methodology...

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

Right.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

...standpoint because I will not be honest if my doctor gets my patient experience data...

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

Right.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

...right? So really what we had to do was, and be, my patient experience definitely...that research shows is connected to and impacts my clinical outcomes, but fundamentally I agree it's not clinical data. It is important and essential and I'm the hugest advocate of experience you'll find, but I understand what Phil's saying. And we had to go to a place where we said, well can we just get questionnaire capacity on the portal, which would...and we did suggest that for Meaningful Use Stage 3, which would enable providers to use their portal to collect patient experience data if they wanted to. But again, it do...but it raises a lot of questions about whether that data goes back into the provider's EHR and if you're collecting on the portal, that's sort of the natural extension.

And so, we create...we have this, hopefully we'll see in the next month or two when we see the draft Meaningful Use regs, we have that capacity in Meaningful Use; but, there's no guarantee that it's going to be used in that way, for some pretty legitimate reasons. So let me, if you're confident that I understand what you're trying to do, let me find a way to thread this needle, because we've had to do this before.

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

I'm good with that.

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

Christine, this is Cynthia. So this is basically saying that the current supplemental questions under the CAHPS Health Information Technology item set are not good questions from your perspective, is that right; because they are anchored in an EHR perspective?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

That's not not...I'm not necessarily saying that at all, in terms of the workgroup's comments, I'm not going to say, I don't think we can say anything about the CAHPS HIT supplement. I do think the CAHPS...personally I think the CAHPS HIT supplement is very weak and it has far more questions designed to measure how many providers have a web site, which is not really a meaningful question to me, and I think it's already a little bit outdated. It doesn't really get...it does get to some good stuff, like does the computer in the exam room gets in the way? But it doesn't get to what Clarke is saying, which is, are you...is the practice or the hospital using their portal and other forms of health IT to collect patient-generated data and is that, in fact, informing my care and are they really respecting what they're getting from me in terms of PGHD.

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

Um hmm.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

That's a whole different ball game and level of measurement that's just not on that survey.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

So Christine, I think your reminder of the question...this is Leslie again; the questionnaire structure with people being able to use that in any capacity they want is a good one. I think that adding of...we'd want to encourage the use of questionnaires for patient-generated health data because what we've found is when the doctor asks the question, they want to know an answer and the patient wants to give it.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Right.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

I think that would be a good emphasis. And yeah, I'm reminded of advance directives that's fundamentally a patient direction or the answer to questions and should be...maybe should be even called out here.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, so I guess I'll make a note about advance directives as well. I think that is something that is missing...well, let's think about advance directives in the next section, too, actually and see how we can strengthen the emphasis there. I just want to remind us...so I'm going to find a way to thread the needle; Clarke said he's okay with that. We've got 15 minutes on the call and we've got one more topic I want to talk about before we wrap.

So, aside from finishing this document so I think we should move on, but I do want to remind us that there are two criteria for...well, three criteria for our comments. One is we need to come from a consumer perspective, which I think we're doing a great job at. Two, it needs to be appropriate for the federal government and three; it needs to be linked to health IT. So patient experience is something that is hard because we tend to really want to blast it out, and we do, but patient experience, in this case, needs to be around health IT, either experience with health IT or how health IT can support it. So, I'm going to focus in those areas and try to again thread that needle. But if folks are comfortable, let's go ahead and move to the person-centered planning objective, which is the next section.

Okay, so hearing no other comments; so I want to give a big shout out to Clarke and I actually didn't mean to leave the stuff green here, but that's sort of a...but it's a good edit or a good indication of the edits that I made based on some things that Clarke had suggested. And for those of you who don't know, Clarke is really...I consider him one of the country's best experts in the care planning process and we've learned a lot from the disabilities community who really does a very robust approach to person-centered planning; not necessarily care planning because it includes care but goes far beyond it.

So I just want to make sure you guys are comfortable with the edits, which is really to clarify that when we're talking about person-centered planning, we're talking about a person-centered services and supports plan. So Leslie, this gets to your comment about bringing everything together, that integrates general healthcare, behavioral health, community-based organizations including those that serve people with disabilities. And let's see here...and then I just put some things that Clarke gave me about showing ONC that this is already happening elsewhere, so they shouldn't think this is something that's completely new, but should be consistent within their own policies.

So I think to Amy's comment, we could probably do a better job here highlighting goals. So perhaps we would say person-centered services and supports plan oriented around patient goals that integrates healthcare, behavioral health and community-based organizations. Reactions to that?

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

This is Clarke, I just want to thank you, Christine and unfortunately I have to run to get downtown for another meeting but I appreciate what you've done and it's very important to the disability community.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great.

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

So, I'll be talking to you on the next call.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

All right, thank you Clarke.

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

And Christine, this is MaryAnne and I wanted to say, too that the model that Clarke has laid out here also very, very appropriate for those of us...for instance, caring for our aging parents, very much applicable.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yes, great and I'm going to add a family caregiver reference to that, just that the process is highly desired by consumers, family caregivers and providers. So that's a great call and let me know if there are any ways to strengthen this. Other thoughts to strengthen or revise or if anybody doesn't agree with this definition.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

One expression that might be helpful would be patient goals-driven care plan.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah. Okay, so let's...all right, thanks Amy, I'm going...I'll add that in. So person-centered services and supports plan oriented around and drive by patient goals which integrates healthcare, behavioral health, da da da da. Okay, any more comments on this?

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

I also wondered if you might want to specifically mention the Administration for Community Living? ONC and CMS were mentioned, and again, I'm agnostic, there's a larger set of issues but it seems to me that as another federal entity, it might be helpful to mention their inclusion in all of this.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, they may be listed, so let's...we'll check the strategic plan, because they have a whole acronym alphabet soup on every one of them. So, we'll check on that; that's a good call, Amy. Thanks. All right, okay, great.

So the next one is ability to identify and support family caregivers. So, we...I don't think we made a lot of changes to this based on comments, although we did clarify it and specifically say that the certification program for EHRs should accelerate the development of functionalities that both identify and support family caregivers.

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

Christine, this is MaryAnne, thank you for that; much appreciated.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great...good call.

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

This is Ivor and this is a question. We don't really have a whole lot of...we don't have any language in here as it relates to children or adolescents when it comes to access to information and who's allowed to access the health information for people and what that means for adolescents in their care and those things that they are allowed to provide care for. So I was wondering if there is someplace, if this is the appropriate place to put just some comment around that or if there's someplace else?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Ivor is there something you think the federal government needs to do beyond the governing laws. I mean, we know what the laws are today with respect to access to health information for minors and for their parents. Is there something we...that the federal government needs to do, number one and number two, that they need to do that's not covered by what we've done here which is to say generally patients, but we're silent as to what kind of patients or how old they are or anything else.

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

Umm, I think it may be covered.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. Okay, but if you think of something, let us know. So the next one is about the "hassle factor" in healthcare; I originally said, well, we probab...very few people felt strongly about this, although Neil, who couldn't join us today, came back and said actually I think we should leave it in not because it's not being addressed by the market in terms of the functions, right, those are definitely out there.

But he's suggesting that the sharing of clinical data is sometimes hard for patients to understand but when they go to a new doctor and all their demographic and insurance information is like pre-populated through an exchange or their portal gives them a summary of their upcoming appointments across providers, then acceptance and use of the portals is enhanced. So, he's suggesting to leave this in, does anybody have a strong sense either way? Okay.

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

This is Cynthia, I mean, if it helps increase the value for consumers and patients, then it seems to me worth leaving in.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay.

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

This is Ivor, I agree.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

All right. What I'm going to do is I'm just going to reframe it and say increase the use of...or increase consumer engagement in electronic health information by addressing the "hassle factor." That's really what we're talking about. Okay.

So the next piece is shared decision making; so what we said was we strongly support advancing shared decision making for consumers and providers, but that needs to be a 3-year not a 6-year outcome. And ONC should assess progress in the field and identify ways to accelerate its presence in the market through certification, payment policy, etcetera. Comments on that?

Okay, so the next piece is around connecting clinicians and patients and families to community resources. So we asked a couple of clarifying questions. We also basically said that it wasn't enough to have a 6-year outcome around identifying innovative uses of health IT to connect to community resources, that by the 6-year mark, you should at least be able to focus on actual using health IT to connect to community resources and social services. And then we have a request to be more explicit around behavioral health and community-based organizations. Any comments on that?

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

Christine, this is MaryAnne. Great additions, in my opinion.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. Good and I was hopeful you would say that MaryAnne because I know you know a lot about this space.

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

Yeah, yeah; awesome additions.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay, good. On the privacy component, so we wanted to call this out specifically. We're basically saying, okay, it's good that you have some things in here, but given the increasing use of patient portals, Apps and devices that are not covered by HIPAA, we need to know what the policy gaps are that ONC and OCR should consider, whether it's...how important it is for the federal government to identify policy options for those technologies and situations where current policy leaves consumers and family caregivers unprotected. Comments on that?

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

My only comment was whether or not you want to put something like innovative technology such as, which leaves open the possibility that it could include things other than just the portals and Apps and so on.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great. Yeah, good idea. Great, I made that edit, thank you. All right, the next is social determinants...

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Christine?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Sorry Christine, just on that, I wasn't quick enough on the button there. Is it appropriate to continue that thought to not only identify the policy options but to do something about it or do we stop there? I take your guidance.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, I agree. No, I think it's more than identify it's identify and advance, right?

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Yeah, yeah, yeah.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

...word, yup. Good. Okay. All right, so the next one, moving right along, social determinants of health. There's a big IOM report on it that had a whole lot of specific stuff on health IT, so basically we're just referencing that but we're saying, it's kind of missing here and the Certification Program under 2B should really foster and accelerate the development of relevant functions, which are definitely in the IOM report. And then we have an addition, and I can't remember why it's highlighted, oh, oh, no we don't. I'm sorry; I'm looking at a different version.

Neil is just suggesting to give some examples. So, for example, tools like screening for social issues, tracking mechanisms for referrals to social agencies and requirements to report on the success of interventions. Any comments about that?

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

Yes, Christine, this is Erin. I just want to make sure that...I like Neil's comments, but I just...I'm wondering if we need to specifically recommend the addition of some kind of a strategy because that's what ONC is going to be using as they describe to us for funding and staffing decisions and such. And I feel like this is such an important issue, especially as it relates to person-centered planning or goal collection and delivering care concordant with patient goals, because so much is affected by these determinants that we need to be stronger and recommend a specific...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

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

...be more specific about where they can include this and lift it up.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yup. So what I'm saying is, ON...so I'm going to make an addition, I agree with you Erin, I think that's a really good call. ONC should have a specific strategy and corresponding outcome that advances the nation's ability to use health IT to address social determinants of health.

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

Yeah, because currently the only thing they have seems to be only related to public health emergencies or disasters.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

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

Yeah, okay. Cool. Thanks.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So the next one is about telemedicine but I want to re-label it access. So...and bas...this is nothing new, we just kind of baked it into the chart. So, yay telemedicine, but we don't see anything around e-Visits, for example and e-Visits would also need to be considered around...for federal policies that support it, like certification and payment. Comments there? Okay.

So, we only have about 2 minutes left so what I'm going to do is take everything from consumers...how consumers drive interoperability down and ask you guys to take 10 minutes once we hang up and send me any edits that you might have. Again, none of this is really new here; in fact, all of this has...we've been tal...we've talked about at length before. I think I maybe had some more narrative under consumers driving interoperability, so take a peek at that. But everything in that third and final section is definitely stuff you guys have seen before, with the exception of participating in research, and this is one of the comments that we got from a workgroup member. So, just take a look at what else is in here, in the table, and send Chitra any other comments that you guys have.

We need to open for public comment. I want to give you guys to ask any last questions you have, but just send me your edits. The one thing that we did not get a chance to talk about today is that our next meetings should be focused on the Interoperability Roadmap. We will be getting a briefing from ONC staff once it's released on what the heck it is, but I can tell you that having been part of I think three briefings now on it for the Policy Committee, it is fairly technical.

So, when you guys sit down for 10 minutes after this call ends and you look at this document and send me thoughts, please also send Chitra any ideas you have about briefings or other prep materials you might need so that you feel really well equipped to look at that strategic plan and...or the Interoperability Roadmap and provide comments.

One of the ideas that I'd like to you specifically weigh in on is getting a briefing on Open API. Open API is something that plays a fairly significant role in advancing interoperability that came out of things like the PCAST report and the JASON Report. I think we would benefit from a briefing on it. Erin Mackay suggested it, I completely agree. So just when you're sending comments on the plan, send comments on what you would need in terms of resources to get up to speed on the roadmap. So, can we...since we're going to...the operator needs to open the lines for public comment so maybe we can start that process and then while we're waiting for people to dial in, we'll just have the workgroup ask any questions that they have. So, do you guys...Kim or somebody want to queue the operator?

Public Comment

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Operator, can we please open the lines?

Lonnie Moore – Meetings Coordinator – 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 telephone and would like to make a public comment, please press *1 at this time.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So while we're waiting for folks to dial in, do you guys have any comments or questions as we wind down?

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Christine, one quick question from Nick; are we involved in any way in the 90-day blocking report or is that operating in parallel to our interest in interoperability?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

I would imagine that's in parallel because I'm not sure what you're describing, but maybe ONC folks on the phone could weigh in.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Umm, Gretchen, are you there?

Gretchen Wyatt, MA – Policy Analyst, Office of Policy & Planning – Office of the National Coordinator for Health Information Technology

I am. To my knowledge I don't think we're asking for any input on the reports at this time. We're still in the process of developing them.

Nicolas P. Terry, LLM – Co-Director, Hall Center for Law and Health - Indiana University Robert H. McKinney School of Law

Thank you.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

I had a question related to the last item you reviewed which was telemedicine or access.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Um hmm.

Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation

This is Amy. And this is about what language we might want to consider in the context of an aging society? So, we normally think about access as being rural or frontier, the ability to access care but in a society with greater dementia and other kinds of problems, there may be other versions of access and also in distance care giving, the ability of the family to participate in the care.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah Amy, you know, you're flagging something that we've talked at length about and I'm realizing has fallen out of here by mistake. We had a section on language access as well and we also talked about access for people with disabilities. So, I feel like that went somewhere that we need to find and put back in. So, thank you.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

We do have a public comment from Scott Brown.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Thank you.

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

Go ahead, please Scott.

Scott Brown – President & Co-Founder - MyDirectives.com

Good morning everyone, this is Scott Brown with MyDirectives. I wanted to...I know I have a short amount of time and you all want to get off the call so I'll be very quick. As always, we wanted to thank members of the workgroup for the important work that you all are doing. Anyone that knows us knows that we're all about consumer and patient voice, so we're particularly appreciative of your efforts.

I was going to make a comment about end-of-life care advance directives critical in emergency care and it looks like Christine and Kelly did a good job of raising that issue. We would just encourage you, as you finalize your comments on the Strategic Plan, and as you consider ways to improve patient-centered care, we want you to keep in mind that at some point we will all lose our good health, because many of these...many of the discussion topics are on recovery and avoidance of readmissions and things like that. At some point we will all lose our good health, whether it's due to chronic illness or catastrophic health events or even just accidents. We will also lose our ability to communicate with our doctors, our caregivers, our family and our friends. So we do believe the concepts of emergency, critical and advance care planning need to be worked into these recommendations and the patient goals and preferences for emergency, critical and advanced care should be the starting point for the conversation with providers and not just an afterthought.

And of course these concepts may seem obvious to you all, to the members of the workgroup, but they are less obvious to outside policy makers and that's evidenced by the lack of attention that topics like advance directives have historically received under the Meaningful Use regulations. As all of you have agreed, you need to be bold and although some members of the workgroup may be concerned that current health IT isn't capable of processing PGHD on emergency, critical and advance care planning, I can assure you that MyDirectives and companies like ours are already helping people create high quality PGHD and making that information available to healthcare providers either directly or via HIEs using APIs and HL7 admit, discharge and transfer feeds that are standards that are adopted and widespread.

So not only is it possible, it's being done every day so we want to thank you again very much for the work you're doing and to give all consumers a voice in their healthcare. Thank you all very much.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Thanks, Scott and that was a good reminder to the group. And so we talked about adding that in on person-centered care planning and I will do that in the next version. Are there other public comments?

Kimberly Wilson – Office of the National Coordinator for Health Information Technology

There's no other public comment at this time.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. All right, great. Thank you guys, please take 10 minutes right now, send Chitra any additional edits you have on that last section and also be on the lookout for an email from the folks at Altarum today that we need you to respond to as soon as you humanly can, hopefully by tomorrow morning at the very latest. That will have some new...a new kind of goal or approach to the goal that we talked about at the beginning of the call. So thanks again everybody, sorry to run over, but it was a very productive call and we'll talk again soon.

Public Comment Received During the Meeting

1. How about putting the very important issue of patient experience of care in the "Elevate consumer voices to shape health transformation" bucket?