



HIT Policy Committee Consumer Workgroup Final Transcript December 8, 2014

Presentation

Operator

All lines are bridged.

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

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

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Good morning.

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

Hi, Christine. Neil Calman?

Neil S. Calman, MD, ABFP, FAAFP – President & Cofounder –The Institute for Family Health

Here, thanks.

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

Hi, Neil. Amy Berman? Bradford Hesse?

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

I'm here.

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

Good morning. Clarke Ross?

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

Good morning.

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

Hi, Clarke. Cynthia Baur?

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

Here.

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

Hi, Cynthia. Dana Alexander?

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

Here.

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

Hi, Dana. Danielle Tarino? Erin Mackay?

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

Here.

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

Hi, Erin.

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

Hi.

Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – 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

I’m here.

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

Good morning.

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

Good morning.

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

Kim Schofield?

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

Here.

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

Hi, Kim. Leslie Kelly Hall?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Here.

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

Hi, Leslie. Luis Belen?

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

I'm here.

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

MaryAnne Sterling? Hi, Luis.

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

MaryAnne is here.

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

Hi, MaryAnne.

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

Hi.

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

Nicholas Terry? Philip Marshall? Teresa Zayas Caban? Theresa Hancock? I'm sorry Teresa you're here, right?

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

Yes.

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

Tripp Bradd? Wally Patawaran? Wendy Nilsen? Will Rice?

Will Rice, MBI – Director Health Informatics – Walgreens/Take Care Health Systems

Good morning.

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

Good morning, Will. And from ONC do we have Chitra Mohla?

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

I'm here.

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

Hi, Chitra. Are there any other ONC staff members on the line? Okay, I'll turn it over to you Christine and Neil.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great, thanks, good morning and welcome back everybody. Let's go to the next slide. The main purpose of our call today is simply to talk more about shaping our work plan going forward. On our last call we had an hour and a half and we spent some good time talking about it but I felt like not everybody got to weigh in and a couple of you have sent in some thoughts and questions after the meeting and so we thought we would primarily use this meeting today to continue that discussion and I'll summarize what that was for any of you who weren't on the line and then we'll continue to go from there.

But, we're going to start with a quick sneak peak at our work schedule so that's on the next slide. Essentially what we are really going to start with next, our most immediate task is commenting on the Federal Health IT Strategic Plan that's being rolled out tomorrow at the Health IT Policy Committee meeting which is a virtual meeting and I think all of you have been invited to listen in on that meeting as well so that you can hear ONC staff doing a deep dive into the strategic plan. So, we will then convene on January 9th and provide feedback on that plan.

I think we will work with the ONC staff in the meantime to figure out a way that we can do some off line work so that by the time we convene on January 9th we're able to have a robust discussion and then we'll finalize our comments, we get to a place on January 9th where we've got enough information to really lay out a draft set of comments so that on January 20th when we meet again we can have looked at a draft of those comments and finalize them and get them back to ONC for their consideration.

So that's what is most immediately on our plate and as you know as well we're then going to probably turn to the interoperability roadmap not too long thereafter, but I think it's a great segue for us to be talking about some of the issues that we think are facing patients and families, and healthcare consumers generally going forward in the context of that strategic plan. So, next slide.

Today we're really going to talk about key trends and issues that we think should be considered and if somebody could advance the slide. Not...I don't know if it's just not working or whatever, but, maybe you guys can turn to e-mail, is it just me or is everybody still staring at the meeting schedule slide?

W

It changed.

W

It's on the slide...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

There we go. Okay, so back up now we went...somebody must have been hammering the button, back up, we've got to go to slide...yeah, okay, here we go, good. All right, so, we talked before about what the key kind of trends that we see out there are, we want to continue that discussion today.

Some examples that we gave you in the path to jog your thinking were any regulatory gaps after Meaningful Use Stage 3, mHealth issues including remote monitoring potentially, health disparities, how consumers advance interoperability which I think we're going to have a big focus on in February and then we also, for those of you who maybe weren't on the last call or just as a refresher, we will collaborate with other Workgroups.

So, the things that we want to talk about and focus on today will be primary areas of focus for us and then we would collaborate with other groups who are already, for example the Tiger Team or actually I guess they're Privacy and Security Workgroup they're no longer a Tiger Team, they're really doing a lot of work around big data and predictive analytics right now and you guys have all been invited to be part of those discussions as well. Okay, next slide, actually just go forward two slides.

So, I wanted to, on slide six, you see that we wanted to remind you guys about the charge for the Workgroup. So, this is really kind of where we're rooted which is kind of these three fundamental areas around how do we use Health IT to engage consumers and families in their own health and healthcare.

Second, how we really enable consumers as partnering with providers and supporting that partnership through Health IT, that's again mostly in, you know, partnering around their care.

And then third, how we ensure that consumers are part of co-creating health system transformation leveraging Health IT that we're not just doing things for them but we're actually designing with them which is why we have a number of consumer and patient representatives on this advisory group as well as family representatives. So, with that let's go to the next slide.

Okay, I'm going to do a quick summary of our last call, the quick themes that we heard and then I'm going to ask the Altarum folks to kindly go back one slide in a minute and, you know, we'll leave our charge on the screen while we talk.

So, I think there were a number of things that we talked about and some of the main ones that we heard repeated as themes you can see on the slides, but essentially how do we begin to connect clinical information like what you'd find in an electronic health record with community-based social supports, you know, community resources, etcetera, how do we begin to bridge that connection and make it easier, because we know a lot of providers already are seeking to do that and are already connecting patients and families with community resources. How do we make the right thing to do, the easy thing to do there.

We talked about what kind of information lives within an EHR that might get us to person-centered quality measures maybe including patient reported quality measures as well.

We talked about how Health IT policy is impacting consumers today, it's a large public investment we've made through programs like Meaningful Use and certification, how is it happening for consumers out there and is there anything cropping up that we need to think about in order to protect the public investment and I'd love to hear more on that topic today as well.

And we also talked about care planning. We talked about a range of care planning including advanced care plans that might also include social determinants of health, also care planning that really helps to document the patients goals, life goals, not just clinical goals and how well their care is concordant with those life goals.

So, that's a high-level summary. Any questions so far about our agenda today or our charge, or anything like that, or should we just dive right in to commenting on the key issues that we see coming down the pike that we as a Workgroup may want to address? And also, by the way, that we may want to look for in the Federal Health IT Strategic Plan and make that they are in there under consideration.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Christine, this is Leslie, there is some really cool legislation that has come out in the past about determining appropriate care so that patients know that when they're involved in share decision making for instance they're getting appropriate care not too much, not too little and there is one effort right now that's on smoking cessation that CMS announced.

And I mention this only because if CMS is already moving towards efforts to get to appropriate care and shared decision making should we consider either shared decision making or informed medical decisions, which is in the ONC interoperability definition, as part of our work effort given that you could potentially ride on coattails in several different areas.

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; just building on that preparing certain populations particularly underserved populations to be able to actively engage in shared decision making and educating communities, underserved communities, who experience health disparities as it relates to how they can use Health IT and how they can be engaged in their healthcare.

I think that's something that should absolutely be in our charge and it is in our charge in terms of disparities, but perhaps we need to get a bit more granular about thinking on those lines particularly how we engage with the community to do that work as well.

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

This is Amy Berman; one of the things...well, we clearly don't have a person's health goal as a major field in the electronic health record which puts us at a significant disadvantage of moving toward person-centered care so this is one thing to consider.

And the other might be to look at similar information around family caregivers. The complexity of admissions and re-admissions around older adults with multiple chronic conditions and acute exacerbations having that kind of information and being able to develop out data on ways to engage that caregiver could be a significant contribution.

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

This is Ivor; I agree I think that’s a great idea and I think perhaps considering that in the care planning process when we talk about care planning that it incorporates all of the people who are involved in a person’s care planning and the ability of that person to incorporate all of those caretakers and caregivers in that care planning process might be a place to consider including that.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Right.

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

Hi, this is Clarke Ross; I agree with all three suggestions and observations I think they’re very important, however, in the immediate regulatory context we need to look at the CMS demonstrations for people dually eligible for Medicare and Medicaid and we need to look at Medicaid managed care regulatory constructs and we’re not even informing potential enrollees and beneficiaries of basic core information, totally ignoring most of who they are and what they want. And in managed care we’re using professional company “care managers” to do all of these things.

So, I agree that all these things are where we want to be but how we use our Consumer Workgroup and the larger Policy Committee to influence some of these things not happening in CMS I think is an...I don’t know where the boundaries are but just want to lay that contextual dynamic out as we’re talking about where we want to see everybody at where they’re not today.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Clarke...

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

This is Luis, Belen, I’m sorry, I agree with everything that’s being said and one of the things that, when it comes to the underserved communities that we may want to look at is trying to implement or make recommendations on targeted accurately resource education outreach initiatives around educating consumers. So, you know, I guess what I’m saying is let’s make recommendations and ensure that from the bottom up as much as possible in terms of how we engage consumers.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So, it’s Christine Bechtel, I want to stop and ask Luis and Clarke, which I think is actually the same question, when you guys talk about...so Luis you talked about accurately resource, you know, outreach initiatives, Clarke you talked about, you know, how we’re informing potential enrollees about basic core information. What are you...so let me start with Clarke, what are you thinking that the beneficiaries or potential enrollees need to be informed about, is it Health IT related or is it something more general?

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

Well, I guess the question on all these issues is what is...can Health IT assist and facilitate where we want to get to and where we’re at, you know, millions of people are just being automatically enrolled in health plans and told this is what you’ve got and then again the so called “care managers” at health plans are making these decisions on behalf of millions of people and all the things we want to see are happening in little pockets.

So, I guess the question is, how can we use the vehicle and forum of Health IT to address some of these consumer rights, consumer protection issues and maybe that's not appropriate and has crossed the boundary, but I don't...I love that we're identifying all these cutting edge things that need to happen and I'm all for it and love it, but we can't do it in the abstract we also have to realize what's happening in the payment world and I'm particularly interested in the public payment world. So, does that help? I mean, does that partly answer?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yes.

Neil S. Calman, MD, ABFP, FAAFP – President & Cofounder –The Institute for Family Health

So, this is Neil, let me throw in a comment here. You know I think you're right on the money. The place that I see Health IT helping is by being able to deliver vetted information because as, you know, we're about to throw a 180 degree shift to people's lives in terms of financial incentives that are in place for the providers that they've been seeing and trusting.

When you talk about shared decision making you need to know a little bit about...I mean, you only have two choices, you either get your information from a completely neutral sort of third-party which is where I think Health IT really helps or you're getting your information and your shared decision making is taking place with a provider who, you know, used to be trying to talk you into doing more things and is now trying to talk you into doing less things because they have financial incentives in place for shared savings and that's happening across the board.

So, I think, Health IT has a critically important part to play maybe not necessarily in educating people about the financial incentives that their providers have, but by being a neutral source of vetted information for people in language that they can understand and explained in ways that they can understand it, because I think people are going to have to be stronger advocates for getting the right care than maybe they've been in the past and we have to provide that information.

I think disparities populations are particularly vulnerable to this because the public, you know, the publically paid entities, Medicaid and Medicare, are jumping out in front on the shifting of the financial incentives and those are the people who are most vulnerable in terms of having not well resourced with, you know, with good information. So, I think...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie and I echo that and also point out that the IOM did a paper released this summer on that very issue and there is a call for certification of shared decision making tools so that they can be neutral and that is ongoing. There is going to be a demonstration project in the State of Washington. So, certifying decision needs so that they are neutral not funded by PhRMA, not funded by financial interests is an important area and certification assures, helps assure, that this is a lever we have as well in Meaningful Use.

Neil S. Calman, MD, ABFP, FAAFP – President & Cofounder –The Institute for Family Health

Right.

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

This is Ivor; I completely agree with what everyone is saying wholeheartedly. In addition to that I think we need to think about how we provide that education and think about a multilayered approach in terms of communicating with the consumer this information in terms of using more traditional consumer engagement or community engagement efforts as well as looking at how we can use social media that’s more actively utilized particularly by younger generations within underserved populations.

And I think it’s really important that we think about this multi-pronged approach and incorporate some of that in our discussions with them about how they’re sharing information with consumers and working with consumers and Health IT.

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

This is Luis, this is Luis, Neil I agree with everything you said. I was just at a meeting recently where we were talking about this care coordination in underserved communities and one of the concerns that I came away with is that as we start looking at these, I believe they’re called DSRIP, as these care coordination models in underserved communities to bring large networks together and I saw the financial incentives in terms of these large hospital systems working together.

What I missed was how are they really getting the communities engaged and this is why I would have a huge interest in trying to figure out how we get...when the federal government puts out these large amount of monies to create these initiatives how do they created some sort of mandate with some of that funding allocated for these specific issues we’re discussing you know.

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

Hi, this is MaryAnne and I want to echo Luis’s concerns about these DSRIPs that have been put into place in the states but I also want to add to our list of things to track and disseminate information about the caregiving legislation that is now making its way through, at the state level, two states I think it’s Oklahoma and New Jersey have actually passed this legislation which requires providers to educate the family caregiver on what they’re going to need to do to support that patient before they’re discharged from acute care. So, I just want to make sure that gets added to our list as well.

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

This is Amy Berman, let me just add to what you just said because that’s really important that the caregiving legislation that has passed in two states and actively going through the process in multiple other states one of the requirements is that the family caregiver also be notified before discharge. So, it would require that the family caregiver is integrated into care planning more generally.

Right now people are handed information at the point of discharge. There is not real preparation. The components of this legislation make it much more real and practical and the role of Health IT in being able to identify and facilitate the exchange of information and the recognition of that family caregiver in the process will be really critical.

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

Hi, this is Dana Alexander, as I'm thinking about this and listening to this I would hope that as a Workgroup that we are really also just...we're identifying, you know, what does a consumer engagement oriented system look like, you know, what are the necessary and foundational types of attributes and how do we really hardwire that consumer/patient engagement that supports active engagement but also passive engagement because I think individuals can be at different levels depending upon the point in time.

And then looking at what are the necessary processes and the models to support that and from there that would build into then what are the technologies and the innovations to support those processes and models.

And of course, as has already been stated, that there is also as a policy indication privacy and security, as an example interoperability and some of the telehealth policy indications that are going on as well.

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

That was a wonderful summary, I think that's great. This is Ivor; I had just a couple of things to add to this, one of those is to think about those people who don't touch the system we haven't really talked about that as much. When we talk about Health IT we talk about the people who are touching some sort of healthcare system, but looking at those other social service organizations that impact on health and impact on outcomes and thinking about how we incorporate that and how we get information on people who don't necessarily touch the healthcare system in that specific way.

And the other comment for me as sort of the person who doesn't know all of the policy things on the state level that you guys are referring to, if there is some way that we could share that information with the rest of group if there is sort of some write up or something that we can have in between meetings where people can look at that, that would be really helpful for me at least.

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

Hi, this is Cynthia Baur, and I want to sort of I guess add to this notion of focusing on the information and education and kind of raise the issue of tasks because healthcare is filled with a lot of tasks for consumers and caregivers, and patients.

And so, in some comments that I sent last week I was wondering about ONC's role and leverage with the vendor community as well as with the purchaser communities, which, you know, we haven't really sort of talked about that, because I'm thinking that there is a lot of things that can be addressed through the design and standards processes, things about the way that information is presented.

So, for example the use of clear communication techniques or the type of education that is provided as well as directions and descriptions of the tasks, the caregiving tasks. So, for example, I was at a local meeting in Kansas City, Missouri a few weeks ago and someone from the community stood up and said “you know if I had wanted to be a registered nurse I would have gone to nursing school. There have been so many nursing tasks that have been offloaded onto me as a caregiver that it’s just really become, you know, unmanageable.” So, that kind of stuck in my head in terms of thinking about kind of a task orientation to all of this because that also takes you into the domain of really understanding some of the literacy and numeracy challenges when you look at this from a task perspective because there is a certain level of literacy and numeracy skills that people have to bring to completing the tasks.

And I think it makes it concrete in terms of thinking about for example what kinds of guidance or standards might be important about the way information and education happens in the context of EHRs and patient portals for example.

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

This is Erin Mackay building on Cynthia’s last point, you know, all of these suggestions have been great so far and it makes me think about whether or not we could approach a lot of these issues from the perspective of those patient portals which are helping to give patients access to their own clinical health information.

To Ivor’s point of course that would only be touching the patients who are already in contact with the healthcare system, but there is a lot of movement in this area and it just seems to me that many of the ideas that were raised, shared decision making, documenting a person’s health goal or a family caregivers some of that could be accomplished conceivably via a patient portal and whether...and also the tasks that Cynthia was just mentioning, and whether there is a role for this group to...you know, with regard to design recommendations, you know, talk more about patient portal usability or design as a vehicle for advancing a lot of these other great ideas.

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

This is Clarke Ross; I think we should pursue Erin’s idea at another meeting. I wanted to make an observation as a follow up to Ivor’s observation. So, we have a whole bunch of people who have no contact with any kind of system but in the area of disability every state has a state funded system for people with serious mental illness, they have a state funded system for people with substance use disorder and they have a state funded system for people with intellectual and other developmental disabilities, and they have a state funded system for sort of, and I hate the term, but like frail, elderly, aging folks with some challenges.

And so it’s not just the people in the healthcare system and the people who have no touch we have these millions of people who are in state funded systems that have operated for decades that are not connected to the general healthcare system and that was the first point on the summary slide seven from last week. So, I just want to make sure that doesn’t get lost in our discussion, but the idea of a portal could be a portal to open the door for all these folks.

Neil S. Calman, MD, ABFP, FAAFP – President & Cofounder –The Institute for Family Health

Well, this is Neil, I think, you know, we're onto a very specific agenda and I think it's a really super important one and I guess I was going to ask Christine maybe or Michelle for some guidance because do we have any idea how this is going to...how the issues that we're talking about now are going to...whether or not they're going to appear in the HIT strategic plan and whether or not these things will sort of be called out, whether or not they're going to be sort of overriding, overlay to all of the issues that are going to come out in the strategic plan. Do you have any idea about that that you can share?

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

Hi, Neil, it's Michelle; the strategic plan is very high-level so I think there are some interconnected pieces to what you've all been speaking about here. They might be at an even higher level. The plan is supposed to be released today and as soon as it is we'll share it with this Workgroup so that you can look for those details.

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

Neil, this is Cynthia, so the agencies within HHS, you know, did a pre-review for ONC and several of us suggested comments to ONC about putting in hooks for the kinds of things that we've been talking about. So, as Michelle said, it is high-level but there are some places to kind of hook these ideas in the strategic plan I believe.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, it's Christine, I agree with that and I think...so I've been making a list I've got everybody's comments down in transcript form but I've also been trying to summarize and get to a more concrete list so that we can perhaps look for some of these themes in the strategic plan and if we don't see them we find areas where we can say, you know, you need to consider how we improve both the content of education and the delivery modes to be, you know, so that it's balanced and it's vetted and we're leveraging Health IT to, you know, deliver it in language that people understand, and literacy and numeracy issues, etcetera, that we would have the ability to lay that out in some of our comments. So, I've definitely been cataloging all of those.

I think, you know, as I think about and listen to everybody's comments patient education, providing balanced and vetted information, shared decision making I think is even a better manifestation in some ways, those issues are important so I think we've cataloged those.

Are there other things though speaking to the task orientation where we need to really think about an understand the workflow of patients and families in the healthcare system and move from where I think our discussion has been focused, so maybe if someone from Altarum could move the slide back one, oh, and actually I lost my Internet connection, but nonetheless.

So, to our Workgroup charge, you know, I think, our comments, a lot of our comments have been focused in that first area of focus where we're thinking mostly about supporting consumer engagement in their own care, their own health.

What I'm wondering is shall we move beyond and think through how we enable the consumer/provider partnerships supported by Health IT. And I think that some of the portal information fits well there. One of the concerns I have is that people are going to end up with too many portals and we're not going to really see tangible data on that until, you know, probably early to mid-next year because Meaningful Use Stage 2 as the early adopters are just kicking off that portal requirement.

So, how do we think about the workflow of patients and families and should we really start to think about them as...they're the only ones present in every visit and every encounter with the healthcare system. They're also the only ones present in their own life outside of that where they have their own health goals and where they may or may not, you know, use education information to better engage in their health.

So, how can we think about patients and families as the only source of really aggregating all of their information across all the different providers and hospital visits and portals that they might have access to and then how do we create a culture of openness among the medical community to really look at the information that consumers are now aggregating in new ways? That's what's on my mind anyway.

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

This is Cynthia; I had a family physician tell me, probably about 18 years ago, that if we could help patients with the hassle factor in healthcare we'd be doing them a big favor.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yes.

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

And, you know, that's always stuck with me as an idea that I've used a lot in my work and, you know, I think a lot about it and I kind of think that's what you're talking about is that...and that's why I brought up this task focus is because...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

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

There are so many steps and directions to complete most things related to healthcare. So, set aside health outside of the healthcare system but just healthcare related and I mean, I think, you know, without belaboring it I think we saw what happened, you know, when people, a lot of people were exposed to new information about health insurance for the first time and had to just sort through that and to connect that information to the explicit task of choosing a plan or not choosing a plan.

So, that's why I think it would be very fruitful to really think about that workload for patients, families and caregivers because it is tremendous even if you have a relatively minor thing let alone, you know, a chronic illness that can become all consuming. So, I would really endorse that.

M

Christine...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie; I'd like to go back to your comment Christine about the multiple portals and things. I think what we can do, we can encourage that data that is provided by the patient, either generated or acting as a health exchange of one, can move into the healthcare system in a secure way that the data can be trusted by the provider.

Now they might have a relationship issue, they may still obviously say, no that's not necessary in the record, but what we can do is have regulations and requirements that the data is known to be authored by this person, held by this person, sent by this person sort of a digital good housekeeping seal that says this data has not been tampered with, this data has been moved on behalf of the patient. So, I think we can encourage the movement of data in a secure way where the patient can control and aggregate.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Because I do believe with the advent of the Blue Button Plus and such we will shift some data movement where the patient truly is at that center. So, anything we can do to encourage the trusting of the data, independent of a relationship that still has to be formed, would I think be highly beneficial.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So, let me respond to that very quickly and Neil I know you were about to chime in. Here's what I'm thinking, we've long talked about the challenge of patient generated health data and, you know, do we need to flag that and how do we deal with provenance and some of these issues that I think you're talking about, Leslie, which is giving, you know, healthcare providers some assurance that it's accurate data, so I agree with that.

What I'm talking about is even broader than that. I'm realizing that as we are looking at things like mHealth and what's happening on-line the ways that we're accessing the healthcare as consumers are different.

So, as an example, I'm going to be doing a Hill briefing today and one of my fellow speakers will be from LiveHealth Online which allows you to have a doctor's visit online for \$49.00. I'm like, wow, you can't beat that, you know, so I decided to experiment with it, as, you know, my duty as a consumer rep, and I visited a doctor on Sunday morning at 11:00 a.m. for 49 bucks who prescribed me, you know, like, well whatever, I won't get into what it was, but that's information that will never ever make it into my record, ever unless I put it there and then if I put it there does it, you know, A how does that...is that process for me to do that and, you know, could I have like a structured care summary for example that would...I could, you know, feed into I don't what, right, my own personal health record of some kind, you know, so there is just a lot of issues I think with...there is another service that I experimented with where I can text with a doctor. So, that advice and that back and forth, again, another piece of information that is really actually clinician generated but is never going to make it into my record and I don't think it should be considered patient generated just because I happen to be the HIE of one, as you were saying, right?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Right.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

So...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

But I think that's one of the reasons why you could say to that provider, hey send a Direct message to Dr. Jones at such and such address.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Right and so here's my challenge...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

I think we should encourage that, yeah.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

How do I get this doctor to be willing to spend the time to do that and then I have to be the one educating the doctor about what the Direct message is and I have to know how the Direct system works.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Right.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

And, you know, talk about adding tasks to the healthcare or I mean to, you know, my plate as a patient or a family member...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yeah.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

But it was just...so we were opening up access but we also have to pull some levers that open up different ways of thinking culturally about the role consumer's play.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yes we do.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

How we shift from being people that need to clearly be educated by the healthcare system or by providers to people who are actually co-producing their own care, totally different...

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

Christine can I jump in?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah.

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

This is Brad Hesse at the National Cancer Institute.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Hi.

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

We're posting conversations about this this week up at MIT on the Connected Health Initiative the President's Cancer Panel is pushing on and I think one thing I'd like to kind of put out there for the group is sort of a first principle or kind of a bigger issue that we can think about, is as I hear Cynthia talk and I hear others talk, and I even hear you talk about some of this stuff, what we're worried about are some of the unanticipated consequences of sort of micro-level thinking on when it comes to engaging patients.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yes.

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

There is...so first off how we figure out how to control these unanticipated consequences there are good system improvement methodologies for doing that and even some marked technologies and policies that Ken Mandl and others have been pushing to try and get at some of that improvement for usability and so on.

But as I think about this I think of the President's Council of Advisors on Science and Technology and the most recent report on healthcare is all about systems and not individual components, right? And so it's all about systems engineering, but when it does that you have to figure out that the patient and the patient's care providers are part of that system and that just hasn't happened at this point. So, I would kind of put that as something very important for this group to think about.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great. Neil did you want to jump in? Neil, I don't know are you still with us?

Neil S. Calman, MD, ABFP, FAAFP – President & Cofounder –The Institute for Family Health

Yeah, I am, no I was just saying that we're sort of passed that point, I think we're kind of...to me the framework and maybe this will be helpful for us, you know, I was looking at the Consumer Workgroup charge and those three bullets that we, you know, that we keep going back to engaging consumers in their own health, the partnership and then the voice, you know, the voices that consumers need to have towards the entire sort of development of the health system.

You know I think it's time for us to consider those sort of the major headings in an outline and start filling in the pieces below that, maybe that would be helpful for us in terms of just organizing this, because I'm feeling like, you know, we're coming up with lists of things and I think we need to kind of organize those lists a little bit. That's just I guess kind of a Co-Chair comment.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yes.

Neil S. Calman, MD, ABFP, FAAFP – President & Cofounder –The Institute for Family Health

And, because I think it's going to be important for us to be able to not just have a bulleted list of things that we're concerned about, but we created this framework and I really like the framework and I think everything that we've talked about can fit within it, but we need to fill out that outline.

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

Neil, this is Luis, along those same lines on the second bullet point in terms of the mandate of the group where we talk about enable consumer/provider partnerships supported by Health IT, one of the things that I would like this group to keep in mind is that in multicultural underserved communities whether it's in Native-American or urban underserved communities we need to keep in mind our providers have not adopted at the same rate as the general population across the board.

And also we need to keep in mind that the provider/consumer relationship in those other communities are crucial and the reason why I point that out is because in those communities to benefit significantly from the work that we're doing there are a lot of these underlying issues that we should just keep in mind as we make recommendations across the board.

And I could give more specific details but I'm just trying to, from my perspective, and discussions that I'm having that's a big issue still in our communities that our providers have not adopted and we're still trying to engage our consumers but how do we do that and that is why I brought up the issue of if there are a lot of efforts that have taken place whether it's through this or other initiatives that we should try to encourage them to make sure that they're doing specific outreach to consumers because they are receiving federal funding and that's...

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Luis, that's really good, it's Christine, do you...and if you want to share or if ONC has any data that help us pinpoint and understand the extent of the problem I think we're probably mostly familiar with the drivers if they're, you know, the usual suspects, but I think some more detail around that problem would help us understand from a consumer view-point what can we do to address digital divide kinds of issues.

Neil S. Calman, MD, ABFP, FAAFP – President & Cofounder –The Institute for Family Health

Well, I would add to that the fact that, you know, really we've seen only one or two efforts nationally in trying to translate the patient portals and so for people that are, you know, Non-English speaking I think we still have a huge issue in terms of patient portals and we still have a huge issue in terms of the dissemination of IT.

If I hear one more person tell me, don't worry about the fact that people don't have computers because everybody's got smart phones, you know, there is still a lot of stuff that's really hard to do on a smart phone. I challenge somebody to look at their whole health record on a smart phone, you know, there is still a lot of things that we're dependent upon in relationship to using computers.

So, I think, that we, you know, we have to deal with those access issues because we're just going to leave a whole group of people out, we're going to be protecting the people who have but without dealing with the people who don't really have access either because of language or lack of, you know, devices.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie, I'd be happy to talk maybe...I see we're getting close on time, but I'd be happy to talk about some efforts I know in Europe that are working on translation efforts at least at the face sheet and at the discharge instructions that although a patient presents in one language and the provider speaks another this kind of information can be provided to the patient automatically. So, I'd be happy to help with that.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great. Other thoughts from folks on either issues we're worried about in terms of their impact on consumers, patients, families or anything we really want to think about making sure it's in the strategic plan and know that I'll take...I think Neil's advice is good which is how can we create an outline using the framework from our scope and begin to put some things under each. I think, the one area that I would point to folks that I think we're probably light on is that co-creating, you know, enabling consumer voices to shape health system transformation.

I think there are...we're a little probably light on thinking about that area although there are some...you know, there's a lot of good stuff happening for example the Federal Strategic Plan Workgroup had consumer representatives on it, we are going to be able to comment as a Consumer Workgroup things like that, but we might think a little bit more about how we can enable those kinds of partnerships. So, other thoughts?

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

This is Ivor; I think we've come up with some great topics today...I know we've been talking a lot about consumer on the individual level, but I also wanted to sort of put forth to the group to think about consumer from a community level perspective because, especially thinking about underserved communities there may be a capacity on a community service level to create a partnership where you can address and meet those needs particularly from the example that you gave talking about...people talking about mobile, there may be an opportunity in working with libraries and working with churches to be able to help people get access to computers in ways that we can do education and communication through a partnership in that way and just to put it out there to think about that as well.

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

Christine, this is Erin, I was also just going to add, I wonder if the Workgroup's focus on interoperability, which I'm so glad to see, you know, continue to be listed on the slides because I think consumers not only have a lot to gain from interoperability but also have a lot to contribute to efforts to develop and build an interoperable healthcare system.

But, I'm wondering if it's in that bucket that we might be able to address some of the Workgroup charge around partnerships with providers because, you know, true interoperability is going to be not just providers exchanging information with each other, but with patients and families, and caregivers, and researchers, and other members of the care teams and that's really going to require, I would imagine, a significant amount of culture shift that gets to the better partnerships with patients.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, okay, great, yeah.

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

On the interoperability topic, I know on the last slide it had a question about resources we might need, this is Erin still, I'm wondering if it would be possible for this Workgroup to get a briefing on APIs because I hear a lot about them as like the solution to interoperability challenges particularly I believe when we're talking about mobile and I'm wondering if that would be a helpful foundation or base for this group to have to be able to, you know, participate more meaningfully in those discussions.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

I think, for me personally, Erin, I would love that. I think that would be great. It might be something we could do either around the strategic plan or certainly in advance of looking at the interoperability framework because it has a heavy focus on open APIs I think.

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

Yeah, I mean, if we could just get somebody to explain to the group, if the rest of the group is interested, exactly, you know, what that means. I know that would be really helpful to me personally.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie, it's important because it's the first opportunity we see where standards can drive, not document exchanging like the replacement of a fax, but actual query-based exchanges and with a patient being able to direct the use of that then we have the first opportunity for things to be highly fluid and if we can come to our work with a context of possibility that this might bring I think it would be very important.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Yeah, great.

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

I would agree.

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

Christine, this is Nick Terry.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Hi, Nick.

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

After the last meeting, this is a little bit off topic in the matter of what you were just talking about, but after the last meeting I sent a note in saying, could the...could our Workgroup be given a sort of summary of the issues that the other Workgroups were going to be looking at during this term and I got a very positive response saying that, yes we would get that, but I haven't seen anything. I'm not sure who was following up on that?

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Chitra do you know? Do you want to speak to that yet?

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

I'm here, yes, I will work on getting a summary to all of you. The Workgroups are still in the process of defining what their charge is, so I was just waiting to get more final approval from Michelle as well.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great and I think we do know that...we do know that the Privacy and Security Workgroup is doing a lot on big data issues right now that we will weigh in on at some point and so you guys are very welcome and invited to listen in on the active deliberations that they are undergoing right now, everything is public as you know.

We also know that the Advanced Care Models Workgroup is supposed to take on the care planning aspect. I think there is a question in my mind about timing of that and when that will occur. So, I'll need to maybe follow up with Michelle and Paul Tang on that topic, but, you know, there will be I think some hooks in places of the Federal Strategic Plan where we can try and advance that work.

The Policy Committee Chairs and Co-Chairs have a call, is it, Michelle, is it monthly or is it quarterly, how are we doing that?

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

It's almost monthly but with holidays and things like that there were a few months that we skipped.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay. So, we do have a call with the other Chairs so that we can all understand what everybody is doing, what issues are coming up and then it gives us an opportunity to say to, you know, whatever Workgroup, hey, you know, what we've been talking about that and we want to engage on that or we're going to hand this off to you. So, that's also good, but I think it would be a great idea to just have a short, you know, snapshot of this group for the next, you know, several months is working on this issue and that's, you know, it doesn't have to be complicated but I think that would be awesome.

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

Yeah, this is Dana, I just really want to encourage for that snapshot as well. I'd love the opportunity to be able to join in these other Workgroup calls, there is a time limitation reality I think for the majority of us where that's just not possible, so to have the snapshot I think would be a really nice reference type of material.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Great, so we have about three minutes left and we want to leave a little bit of time for public comment, but does anybody else have any burning issues, questions or comments that they want to share before we close? Okay, so, and I know Neil had to drop off the line, but Michelle do you want to open the line for public comments.

Public Comment

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

Sure, operator can you please open the lines?

Bess Hoskins– Specialist – Altarum Institute

If you would like to make a public comment and you are listening via your computer speakers please dial 1-877-705-2976 and press *1 or if you are listening via your telephone you may press *1 at this time to be entered into the queue.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay, so while we're giving folks time to call in, just in summary, what we will do going forward is we will summarize today's call and try to bracket out the issues that everybody has raised into descriptors underneath each of the three areas from our charge and those will be issues like patient education, you know, balance and vetted information, different modalities or delivery channels, how we identify and support family caregivers, how communities and consumers are engaged together, making sure we understand the tasks that consumers and family caregivers have to perform and how do we make those easier through Health IT, patient portals, usability, design, the multiple portal issue, how we might begin to recognize consumers as legitimate sources of data and doing kind of a digital housekeeping seal of approval, equitable adoption in Health IT underserved provider communities, interoperability, patients partnering with providers, unanticipated consequences of patient and family engagement how to track and address those, connecting the community resources, mHealth and care planning coming from our last discussion. So, I think those are the main areas that I cataloged today.

Our next meeting is going to be January 9th so be on the lookout tomorrow's Health IT Policy Committee the Federal Strategic Plan will be rolled out, be on the lookout for information from us asking you to, you know, maybe look at and consider some key questions that we can have a productive discussion on our next call around the strategic plan. Are there public comments?

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

We have no public comment.

Christine Bechtel, MA – President – Bechtel Health Advisory Group

Okay, all right, great, so everybody thanks again for your time, have a terrific rest of your week and let us know if you have any questions or additional thoughts via e-mail.

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

Thank you.

M

Thank you.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Thank you.

W

Thanks, Christine.

W

Thank you.

W

Thank you.