

**HIT Policy Committee  
Consumer Empowerment Workgroup  
Transcript  
April 23, 2013**

**Presentation**

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thank you. Good morning everybody, this is MacKenzie Robertson in the Office of the National Coordinator for Health IT. This is a meeting of the HIT Policy Committee's Consumer Empowerment Workgroup. This is the second meeting of this workgroup. There is public comment built into the agenda. The call is also being recorded, so please make sure you identify yourself for the audio file. I'll now go through the roll call. Christine Bechtel?

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

Good morning.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks Christine. Korey Capozza? James Cartreine? Scott Fannin? Leslie Kelly Hall? Katherine Kim?

**Katherine Kim, MPH, MBA – San Francisco State University – Health Equity Institute Professor in  
Residence**

Good morning.

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

Thanks Katherine. Sarah Krug?

**Sarah Krug – Cancer101 – CEO**

I'm here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks Sarah. Rita Kukafka?

**Rita Kukafka, DrPH, MSPH, FACMI – Columbia University**

Good morning.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Good morning. Thanks Rita. Patricia MacTaggart?

**Patricia MacTaggart, MBA, MMA – George Washington University – Lead Research  
Scientist/Associate Professorial Lecturer**

Here.

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

Thanks Patricia. Beth Morrow?

**Beth Morrow, JD – The Children's Partnership – Director, Health IT Initiatives**

I'm here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks Beth. Jan Oldenburg?

**Jan Oldenburg – Aetna – Vice President, Patient Engagement**

Good morning.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Good morning Jan. Casey Quinlan?

**Casey Quinlan – Mighty Casey Media, LLC – Chief Message Officer**

Present.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Great. Thanks Casey. Clarke Ross?

**Clarke Ross, DPA – National Quality Forum**

I'm here.

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

Thanks Clarke. Mark Savage?

**Mark Savage, JD - Consumers Union of United States, Inc.**

Good morning.

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

Thanks Mark. MaryAnne Sterling? Ann Waldo?

**Ann B. Waldo, JD – Wittie, Letsche & Waldo LLP**

Good morning, I'm here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Oh great. Is that MaryAnne or Ann?

**Ann B. Waldo, JD – Wittie, Letsche & Waldo LLP**

That was Ann.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Ah, thanks Ann. Ryan Witt? Terry Adirim?

**Terry Adirim, MD, MPH – Health Resources and Services Administration – Director, Office of Special Health Affairs**

I'm here.

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

Great, thanks Terry. Cynthia Bauer? I believe Cynthia is on the line. Bradford Hesse?

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

I'm here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Great. Thanks Brad. Is it Brad or Bradford?

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

Brad.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Great. Okay. Kim Nazi? Danielle Tarino?

**Danielle Tarino – Substance Abuse and Mental Health Services Administration (SAMHSA)**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks Danielle. Teresa Zayas Caban?

**Teresa Zayas Caban, MS, PhD – Agency for Healthcare Research and Quality**

Good morning.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Good morning Teresa. And if there are any ONC staff members on the line, if you could please identify yourselves.

**Lygeia Ricciardi – Office of the National Coordinator**

Lygeia Ricciardi's on.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks Lygeia.

**Erin Poetter Siminerio, MPH – Office of the National Coordinator**

Erin Siminerio.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks Erin.

**Mary Jo Deering, Ph.D – Office of the National Coordinator – Senior Policy Advisor, Office of  
Policy and Planning**

Mary Jo Deering.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks Mary Jo. Okay, with that, I will turn the agenda back to you Christine.

**James A. Cartreine PhD – Brigham & Women's Hospital/Harvard Medical School**

And this is Jim Cartreine. Sorry I dialed in late.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Oh great, thanks Jim.

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

Thanks MacKenzie and thanks everybody for joining us at our second meeting. You have an agenda that was sent out, but essentially, we spent a good part of the last call sort of going through a great series of introductions and getting to know each other a little bit, and we'd like to focus this call on understanding from ONC some of their work that relates to consumer engagement. So we're delighted to have both Lygeia Ricciardi and Erin Siminerio talk about ONC's consumer engagement strategy, talking about some of the trends and the environment and then we're also going to hear from Mary Jo Deering about a technical expert panel that ONC has on patient-generated health data.

So, with that what we want to do is to really develop at least the beginnings of a work plan for the group. And thinking about, as you hear from Lygeia, Erin and Mary Jo, what is it in the environment that is pressing, that we would really benefit from having some policy around, either because it will accelerate the impact of certain activities or trends or because we see technology kind of outracing policy, for example. We want to make sure that our starting place is a good one. As you guys who were on the last call remember, we did do a fair amount of discussion around shared care plans, because they have been a hot topic as of late. But before we decide that that's our first focus, out of the box, we really want to understand from ONC what's happening in the broader health IT policy world with respect to consumer engagement.

So as you go through and hear from ONC over the next 30 minutes or so, they're going to do a deep dive, and I'd love for people to pay attention to what feels pressing to them. What feels like an area where this group could have a real substantive and tangible impact in the short and medium-term? And then what we'll do is turn to a discussion with all of us around what that work plan should look like, what's our immediate next step, for example. So with that, I will turn it over to Lygeia.

**Lygeia Ricciardi – Office of the National Coordinatory**

Okay. Thank you, hi. Just to make sure we're using time effectively, are we – basically we've got about 15-20 minutes, right?

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

I actually think you have 30.

**Lygeia Ricciardi – Office of the National Coordinatory**

Okay. Excellent. All right, so welcome everybody, thank you again for joining us. Do I have the power to change slides or could I request that someone flip to the first slide.

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

Actually Lygeia ...

**Caitlin Collins – Project Coordinator, Altarum Institute**

We can give you...

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

Sorry, I mean 30 minutes for ONC total, split between the three of you, so I don't know if that clarifies things for you.

**Lygeia Ricciardi – Office of the National Coordinatory**

Okay. So that speeds me up. It's going to be mostly sort of me and Erin and then some time for Mary Jo. So, I'll keep it more sort of 10 or 15. Okay, on the slides. Could we – okay, excellent. So welcome. Basically, as Christine said, the idea here is to familiarize you, those of you who are not yet familiar with the kind of work that we already have underway and the strategic framework in which we've situated it. Some of this may be new to some of you, but not to others, although some pieces may be new. Okay. I am trying to flip slides here, and it's not working.

**Caitlin Collins – Altarum Institute**

We haven't given you the rights yet, would you like them?

**Lygeia Ricciardi – Office of the National Coordinatory**

Ah, it's entirely up to you. I can do the ...

**Caitlin Collins – Project Coordinator, Altarum Institute**

No, no it is up to you, you can just say next slide and we'll move it ...

**Lygeia Ricciardi – Office of the National Coordinatory**

Give me the ability to flip the slides and that'll make it easier. Terrific.

**Caitlin Collins – Project Coordinator, Altarum Institute**

You got it.

**Lygeia Ricciardi – Office of the National Coordinatory**

Okay. So I want to move from this one ...

**Caitlin Collins – Project Coordinator, Altarum Institute**

The arrows are in the bottom left.

**Lygeia Ricciardi – Office of the National Coordinatory**

Gotcha. Beautiful. Okay. So, bottom line here is that engaging consumers is tightly integrated into ONC's overall vision and strategic plan, which it outlines not just for ONC, but for the federal government in general, with respect to health IT. And this is a document that we put out about two years ago, approximately, a little bit less, which laid out five major goals for health IT, the fourth of which was empowering individuals with health IT to improve their health and the healthcare system. So although this is an idea that has been growing in its emphasis at ONC and beyond, it's certainly been grounded in our work and our thinking for a couple of years and even beyond that. Outside of ONC, of course, there are great, I think, forces that are really pushing consumer engagement forward. Among them, policy, mostly health reform and in general, the switch or general migration from payment for volume to payment for quality of care; of course, changes in technology. I mean, we all hold in our pockets cell phones that are as powerful as big computers were 10-15 years ago. And there's also a greater demand from consumers and the public for information generally, in all – about all kinds of information, including increasingly, health information. People are not just demanding information but they're connecting to one another to share ideas and to learn from one another.

So what this slide basically gets at is that there is this untapped demand. People want these kinds of services and the ability to connect to one another, but they don't yet have it. So there are a lot of studies that show that people want to be online to share information, to get their information from their providers and so on, but only, depending on the studies and the particular tool, roughly 10 percent of the population is really participating in using PHRs and similar tools. There are others who are using smart phones increasingly for health and so on, but the supply, or the use of these tools really hasn't caught up to the underlying demand.

So what is ONC doing about it? Well, our strategy, and the way we kind of think about this whole challenge is based around a strategy which we call the Three As: A is for access, action and attitudes. So, attitudes is about shifting attitudes to support this patient and provider relationship, it's about changing old norms and ways of thinking about the way in which patients and providers interact, which traditionally often involved the provider simply kind of giving directions and the patient following them. We want to see much more of a collaborative model. And those things, you've got this sort of circle up here showing that all these things are interrelated.

Access to information is a key part of having that kind of collaborative information. So, a lot of what ONC does is try to make that information available to consumers in electronic format. Action addresses the need for people to take action with their information, just getting a whole lot of access to data, whether electronic or not, doesn't do a lot for you if you can't really incorporate it into what your goals are as a patient. So it's in this context we tend to work as a catalyst, convener, vision setter, policy maker, but the big point is that we see all these forces that I just mentioned, technology, policy, outside forces are driving this. Patients themselves really want to be engaged in health and healthcare and we're trying to catalyze and support this movement, but we don't see ourselves as out there leading it, per se.

So, to get into some specifics about what we're doing in each of these three prompts. It's shifting attitudes; one of the key elements that we have, one of the key tools we've created for a broad array of stakeholders is HealthIT.gov, which is the HB ONC website, which has a section specifically for consumers, which we are very much evolving. But we had a lot of input from consumer advocates, patients and others in shaping its content. It has a lot of tools, including videos. For example, you can see at the bottom right, a little bit, you can't really see. We have a video called Health IT for You, which is an animation that makes the whole topic of access to your information and engaging with your health, hopefully a lot more compelling and fun than it might otherwise be. So, we've also run a series of contests for individuals, getting them – effectively crowd-sourcing public service announcements from members of the public about how they've used technology to improve their health.

And the access piece, the biggest lever that ONC has in many ways is, of course, meaningful use. And so we have very much incorporated the idea of patient access to data into, especially in Stage 2 of meaningful use, in which any participating provider will need to enable patients to view, download and transmit their health information. This is a very big step forward, it's certainly building off of the right that was articulated initially in HIPAA, that people have a right to access their own health information. And will soon be further clarified in an electronic format, to show that if information is in electronic format, patients should be able to get it in that format, if they request it in that way. Building on meaningful use is Blue Button, generally. So Blue Button is similar to meaningful use in that it's about access to data, except that it's broader in that it's a term and a brand and a logo that can be used, either in the context of healthcare providers or payers. In other words, it can be used by folks who have nothing to do with meaningful use directly. And it was developed by the VA and actually is a very simple symbol that they give me access to my data.

So, moving along here. As I said, meaningful use very much supports patient access to data and we're thinking about that, not only in Stage 3 – 2, but also in Stage 3, in which we're really thinking hard about ways to enable patients not only to access data that providers or payers hold on them, but also to be able to give feedback, share their own patient generated data or jump in and say, hey, I think there may be an error or an omission there. So in terms of the access piece – or the action piece and enabling people to really take action with their data once they have it. First of all, we – one of the major areas we've focused on is helping the developer community to build tools. Our idea is that by in a sense liberating the data through Blue Button and through meaningful use, there will be a lot more consumer information flowing electronically. And we want to make sure that the community of developers and other investors and so on, are ready to build tools and applications that are appealing to consumers.

So, we wanted to improve on Blue Button as it was initially thought of. It was first built by the VA, as I said, and it was put out as an easy way for consumers to get access to their data. It was initially put forward in ASCII text files or PDFs, which is very hard to work with, for the developer community. So basically we held a meeting in which we pulled together a variety of stakeholders, including folks who are entrepreneurs and said what do you need in order to build better tools. And they said, well, we need more structure, we need consistency, we need secure transport, we need basically seamless information. They told us about the limitations of Blue Button and health data as it stood, and really helped us. From that meeting, we convened a group of about 68 experts through our Standards & Interoperability Framework, who helped us work on something called Blue Button Plus.

Blue Button Plus is a set of defined guidelines and standards that address those shortcomings in just general Blue Button, as I mentioned. And very importantly, it has a very good relationship with the requirements in Stage 2 of meaningful use, the view, download and transmit requirements, in that it basically builds on those, just by making them a little bit stronger. In order to further strengthen the work that we'd done in Blue Button and Blue Button Plus, we've also been using a variety of challenges, which are essentially usually contests with a prize associated, which is usually monetary, to have people build things where we see that the market hasn't been meeting a particular need. And one of the goals of this is not only just to get a certain type of tool or service built, but to really encourage new entrants, who hadn't been participating in the personal healthcare space to jump in and start understanding the market here.

So we put out a challenge last year called the Blue Button Mashup Challenge in which we encouraged people to take Blue Button data and mix it with other kinds of data, environmental, lists of medication lists, other kinds of things, and provide useful apps and tools. And you can see on the screen some of, several of, the three winners actually from that program. And that was kind of an early stage challenge related to Blue Button, I think in the future, we're thinking about potentially doing a challenge for Blue Button Plus, specifically, so that'll be using much more structured data.

Another challenge that we did had to do with designing the visual display of health information. And so we challenged participants, and this had a large participation from the design community, to use data from the CCD, the basic data that is exchanged in meaningful use, and envision it in ways that were much more user friendly. And we got some really impressive results back. We also ran a pilot, and quick handing the baton over to Erin, this is one of the things that Erin's been overseeing. We did a pilot related to patient's ability to give feedback on their data. You want to jump in for a second Erin.

**Erin Poetter Siminerio, MPH – Office of the National Coordinator**

Sure. Thanks Lygeia. So, we worked with NORC to do a research literature review and environmental scan, and also a pilot at Geisinger Health System, to really test the extent to which patients could be effectively engaged in reviewing their information for accuracy and completeness. And sort of testing the assumption that patients want to or are interested in playing a more engaged role in reviewing their information and providing feedback into that information. What we found is, I think, of no surprise to folks in the patient engagement community. The response to the opportunity for patients in advance of an official office visit to review their medication list online and to actually submit feedback on the list to indicate whether or not the information was correct, whether there were any medications that were missing or perhaps whether there were any corrections that needed to be made.

We found that – well we were surprised to find that patients were really excited about the opportunity to provide feedback, 30 percent of patient feedback forms were, in fact, completed and submitted to Geisinger. Again, indicating there was a strong interest in engagement. And then in 68 percent of cases, the pharmacists actually went in and made the changes to the medication list in the MyGeisinger EHR, which again indicates that patient feedback was actually very valuable. Obviously, patients know themselves best and what they are taking at the time. So, that was also very positive. And then finally, we found that patients, the feedback that they were providing was valuable in that they caught at least two changes per form, so again, errors or omissions in their records. So I think this is just a great – another example of a great use case for engaging patients and in reviewing their information and ultimately improving the quality of the information being used to make decisions about their care.

Next slide please. So I also wanted to mention that there is a Blue Button Pledge Program, that sort of doesn't fit nicely into any of the three A's that Lygeia just reviewed, it sort of cuts across all three of those areas of our program. And this is our Blue Button Pledge Program. This is the way in which we're able to work closely with a number of organizations to kind of build momentum and also build collaborative opportunities for these organizations to work together to advance consumer access to their data and use of that information to improve outcomes. We actually kicked off this pledge program in September of 2011 with 30 initial organizations and since then it's grown to 450 organizations today. And we bring these groups together through webinars and in other ways to again sort of learn from each other about the ways in which they are making advancements in giving consumers easy electronic access to their information.

There are two types of pledges. There are organizations that have data, like large health systems and health plans, who are pledging to make it easier for people to get their information. And then there are other folks in this community who we call non-data holders, which are the advocacy organizations and developer community who are either building tools to help consumers use their information and make meaningful use of it, or are helping to spread the word about the importance of getting a copy of your records, reviewing that information and playing a more engaged role in your health. Next slide.

So finally, I just want to mention that our entire strategy is that – well, it was recently published in a health affairs article that was in the February special issue on patient engagement, which we can send out a link to the full text of that, after the call. But we've also recently posted parts of our strategy on an innovative new platform called PlanningRoom, where we are seeking additional public comment on some of the work that we're doing. The platform is live today and we are accepting comments through May 9<sup>th</sup>, so a little bit of homework for folks on the phone, we would encourage you yourself to comment on our strategy. But also to kind of spread the word through your network to get other individuals engaged in also commenting on our process and some of the topics, and questions that'll help us guide our strategy in the future.

**Lygeia Ricciardi – Office of the National Coordinator**

So, just to wrap up, and I want to make sure, I know we've cut into Mary Jo's time, but there's a lot going on, some of which is within the kind of Office of Consumer eHealth, where Erin and I work, but there's also, of course, a much broader integration of consumer related activities across ONC. We haven't delved into all of them. Mary Jo will touch on another, but there are certainly other things in the works, too, that we can touch on in discussion. Thanks.

**Mary Jo Deering, Ph.D – Office of the National Coordinator – Senior Policy Advisor, Office of Policy and Planning**

Okay, I guess it's over to me. So if we could take the next slide please. This is Mary Jo Deering, hi. And if you remember Lygeia's slide earlier on that showed the stages of meaningful use, and it showed that in Stage 3, we were moving toward much more use of patient-generated data and their ability to make corrections. And so for those of you who are in the Meaningful Use Acronym business, you know that in Stage 2 VDT, standing for view, download and transmit, is really one of the major breakthroughs for patient engagement. And I sort of like to think that maybe for Stage 3 it'll be VDTCC for correct and contribute. That's certainly the direction that, under Christine's leadership, that the Meaningful Use Workgroup is going right now.

So, the Office of Policy and Planning doesn't usually get involved in the programmatic side of consumer eHealth, we try to help sort of paint the landscape or work on things that are a little bit into the future. Now in this case, OPP is taking the lead on something that is both immediate, but in the longer term, around patient-generated health data. We asked our cooperative agreement partner, the National eHealth Collaborative, to convene a technical expert panel, to give us some insights on how you could successfully implement patient-generated health data. We wanted to do it in two phases; phase one is more immediate, where we hope to identify some good practices, promising practices that can support the areas of patient-generated health data that are emerging in Stage 3. And then the panel will turn its attention more toward the future, and even outward, beyond Meaningful Use Stage 3, to continue its work, to look a little bit more innovatively at opportunities for patient-generated health data.

This work is important because while there is great enthusiasm for the potential and the value of getting information from patients, providers are, I think there's nothing more to be said than it really scares the heck out of them sometimes. They have visions of a fire hose of data coming at them from a variety of sources that they can't control, and they are legally liable for receiving information and acting on it, if it's available to them. So, there are some very real concerns about, and policy issues around how patient-generated health data can be most effectively promoted, processed, used and ultimately influence health and care. So, let's go on to the next slide please.

So in this first phase of work, the panel's going to be looking at 3 different recommendations from the Meaningful Use Workgroup. The first one that you see on the – up on the slide right now is the most specific patient-generated health care, specifically calling for the input of data around high priority health conditions or patient engagement in care. The next slide please. There are two others that we think go hand in glove with it, the first is this ability to request an amendment and offer corrections. And then the next is the use of secure electronic messaging. And we believe, at least the panel is looking at all three of these sort of together, because after all, the ability to offer a correction is a form of generating data, and using secure messaging is a channel for doing that. So, next slide please.

So what they're going to be doing for Stage 3 is coming up with some promising practices to help providers know how to move forward in implementing these good opportunities for patient-generated health data. The guidance will look at what an organization needs to do to prepare for this, how to identify data that's of value to patients, as well as to providers, and guidelines around processing it. We hope that this report will be ready in the near future, to be shared with the Meaningful Use Workgroup and the Policy Committee, to the extent that it's valuable. Again though, the audience for this work is specifically providers, to help sort of lower their anxiety level around the perceived difficulties of implementing patient-generated health data. Next slide please.

This next project is not at all near or even medium term. In fact, we sometimes talk of this as the person at the center, 20/20 vision. This pulls together some thinking around a new model of, a new paradigm of ways to think about health and care that certainly won't sound new to I think most of you on the phone, but I think you've been in this business long enough to know that this is a slow, hard slog and we need to be pushing hard to move forward in this area. So again, it's a much more person-oriented look and it's not at all a medical model look at health and care, so we want to unleash their ability to manage their health and partner in their healthcare. Next slide please.

And we look across the continuum from wellness to illness, and from self-management to shared management. Next slide. I'll talk a little bit more about what we mean in these domains. So on the – in the area of self-management and prevention, we know that not only for staying healthy and the things around exercise and nutrition, but there are a lot of conditions that are self-managed, sometimes for years and years without a providers input. And so there are a lot of things that individuals do need to do, to stay healthy without contact with a physician. And so there needs to be more work done to identify good Health IT support and resources for activities in this domain. Next slide please.

And then there's this middle ground where people are – they have connections with the healthcare system, with their provider, but this is just about that sort of interaction, that interim, that intermediate area where they need to know when to go in, they need triage for example. They need to be able to do some easy functional things like schedule appointments or ask a question, and we think that strengthening activity in this area will again be very beneficial to reducing unnecessary care. Next slide please. And of course in the shared management area, the concept of shared decision-making is very important and one of the important elements here is care givers are recognized as part of the care team, along with the patient. So, we need to develop both the policies and the programs that can help move this area along. Next slide please. This'll be my last slide.

So we want to begin to work on some building blocks for getting to this vision. There certainly is a lot going on in this area already that we can build on, but we want to pull together this set of policy ideas that can be really game changing. That can be not just tactical for the next six months to 12 months, but looking further ahead of what's going to be needed to change the individual cultures and the institutional cultures that will need to change if we're to achieve this vision. So, we'll be working on these building blocks over the next three-to-four months and will certainly make more information available to you and we'll be trying to learn from you about what inputs can help move us in this direction. So, I'll stop there.

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

Thank you Mary Jo, that was terrific. And thank you to Lygeia and Erin as well. So, let's take the next few minutes and ask some questions of ONC based on what we've heard and then we'll have a discussion about what we think are the most important areas to focus on. And I'll ask somebody to advance the slide one, so that you can see some of the questions that we need to think through for that part of the discussion. So if somebody can advance the slide by one that would be great. Perfect, uh oh, yeah, one back. Thank you. All right. So questions for ONC from the workgroup?

**Rita Kukafka, DrPH, MSPH, FACMI – Columbia University**

Hi, this is Rita Kukafka.

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

Hi Rita.

**Rita Kukafka, DrPH, MSPH, FACMI – Columbia University**

Yeah, so one of the – I mean, this looks great and thank you very much for the presentation. The one thing that I have a fairly significant concern about is the potential of this for increasing health disparities. And my question is, to ONC, how is that being addressed.

**Lygeia Ricciardi – Office of the National Coordinator**

Erin, do you want to take that one?

**Erin Poetter Siminerio, MPH – Office of the National Coordinator**

Sure. I'd love to. So we recently hosted a summit at the White House aimed at answering that question, so how do we achieve eHealth equity for all Americans and make sure that everyone can benefit from access to their information from the use of these tools. And that we are conscientious of making sure that certain groups are also involved in the development of some of these tools and making sure that they resonate with those populations. And we had a really great discussion, I think. We ran out of time because we only had a half-day to meet with folks.

But what came out of that gathering, and Christine was there in the room, so she might want to also add on her thoughts, as a participant. But we are planning to publish in the next two weeks, a summary of some of the key takeaways or findings from that session, which we hope to use as a launching off point for great discussion about how we ensure eHealth equity for all Americans. So I think we have certainly started that conversation and there has been prior work as well, there's been a health IT disparities plan that was published a couple of months ago, and some other work too that fed into the session. But, we've been working very closely with the Office of Minority Health and with others to take a really – a closer look at this issue.

**Mary Jo Deering, Ph.D – Office of the National Coordinator – Senior Policy Advisor, Office of Policy and Planning**

This is Mary Jo. I just wanted to add that we certainly heard that concern in our early consideration of the person at the center vision, and you won't be surprised to know that Cynthia Baur, who was part of those discussions, made sure that certainly the concepts of health literacy were firmly embedded in this vision. And other people added the concerns that you've raised and the emphasis on caregivers and community support, so, thank you for reminding us of that and we appreciate it.

**Rita Kukafka, DrPH, MSPH, FACMI – Columbia University**

Yeah, I have a, just a follow up to that. And having been someone who worked in this field both before the technology that we have now and after, related to the issue of health disparities, but maybe more subtle, is this problem that we've dealt with for decades, and that's one of salience. That the idea of self-management and taking a proactive position on your health has always been problematic because health for most is not salient unless you have a condition that you're concerned about. So a lot of this seems to be directed towards consumers who are thinking about their health and yet we know from work in prevention that that's often not sufficient, because most people don't think about their health.

And I'm wondering if there's – I know these are difficult questions, I'm just raising them as issues, and I don't really expect answers, I just want to put it on the table. That the issue of both health disparities and the issue of salience, that health is not on the top of most people's mind unless they become ill, has been a problem in prevention and engaging consumers at phases that were mentioned by the speakers, which is more towards prevention and management.

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

So Rita, its Christine. What I'll say is I agree it should be on the work plan, the topic is broad, however, so we would want to look pretty specifically at how health information technology policy could impact health disparities in the future. And I think the trigger for us is going to be the advent of the unlocking, if you will, of a lot of patient data that we will now be able to have access to ourselves. And looking probably, in particular, at mobile platforms and being sure that policies do support, and then of course our sister group, the technology workgroup, making sure that standards support mobile access to your on personal health information, because number one, it does help people think about their health who may or may not be already. And number two; there are no disparities in cell phone adoption rates, for the most part. So I think that's something that we can put on our work plan for the future. It's something that I requested be on the Policy Committee's larger work plan this year and so I think it may be the third quarter. So, we'll go ahead and put that on the work plan. I think the question we have is: What do we need to focus on first?

I will say this, while I have the mike and then I'll open it up for more questions and discussion, that I think the big event here is we're going to have data from multiple physicians and hospital visits beginning to be available to consumers on a widespread basis, beginning in January. And so I heard...the themes that I heard from ONC were around trying to figure out this issue of correcting data, adding to it where things, important pieces have been omitted, which does give some people heartburn. And so I think that's something that's going to be very important as well. The other thing that I heard in ter – and I had a question for Lygeia, on the design of health information project on slide 15 that you guys worked on. And I was wondering what the context was, was it design of health information in a PHR or a care plan or was there a particular vehicle that you were looking at?

**Lygeia Ricciardi – Office of the National Coordinatory**

So, let me respond to a couple of those thoughts, Christine. One is, I think you're – I like the way you talked about the challenges that will come up. These are good challenges as Meaningful Use 2 is implemented and patients are getting a lot more data than they ever did in the past, and this challenge of adding data, correcting data, but also I would add to that list, reconciling data. It's a kind of correction of data. But what do you do if you get data from three different providers in your health plan, and it doesn't all match up, and how do you figure out how to take action with that? That's a complicated issue. I don't know the answer to that, but it's one that concerns me.

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

Yup, I agree.

**Lygeia Ricciardi – Office of the National Coordinatory**

To your question about the design challenge, we didn't specify what the exact context would be except to say that we used the information in the CCD, so those basic fields, and said, how can you present that information in a way that it is appealing and actionable, particularly for patients, but also for providers, on a variety of platforms. So that's pretty open-ended. And I should add that the California Healthcare Foundation contributed some funding to actually code some of the winning designs, so that now the designs are out in the public domain, people can copy them, but within a month or so people will also have access to open source code that they can use and incorporate into different products. I think part of the theory though is if you can make information actionable was kind of the key salient points for patients, that will also be useful for providers and others, even if it may not change the way say EHRs are structured initially, it's something that can be used to really get conversations between patients and providers going.

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

Great. Other questions of comments from workgroup members?

**Jan Oldenburg – Aetna – Vice President, Patient Engagement**

This is Jan Oldenburg.

**Ryan Witt – H4Y Corp**

This is Ryan Witt. Can you hear me okay?

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

Yup.

**Ryan Witt – H4Y Corp**

Okay. I think that the one thing that I wanted to really emphasize is the action ability that you just mentioned. I mean I think that one of the keys is to make data actionable for consumers and that's what will drive adoption. And I know that one friend here that, in a different sector, in the budgeting world. One of my friends in the Bay Area started a company to use text messaging to help going – this is addressing kind of the health disparities, but he started a company to help people manage their budgets using text messaging instead of smart phones, to help people who couldn't afford smart phones. So one idea to help with the health disparities is to somehow think about incorporating text messages, although if the data that you guys are seeing shows that there's no disparity between like smart phone usage and between people in different economic statuses. I mean, maybe that's not as much of an issue. But I definitely think action ability is key.

And one of the areas that I can touch on is, with my – the company that I was formerly with, Drchrono, I think that one of the things that was exciting that I started to see is with some of our customers. They actually wanted – the customers being doctors, they actually wanted to see more information in our EHR and linked up with different devices that they used to monitor care. One of the things that we found was it was somewhat specialty specific, but I think that that can be leveraged somehow if you could see some of the different tools that were maybe specialty specific that a doctor wanted to use and see, and then they could somewhat prescribe to their patient, and say hey, I really want to see this information, and try and get their patient to use it.

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

Great. Thank you. And I'm going to ask for ...

**Jan Oldenburg – Aetna – Vice President, Patient Engagement**

Hi, this is ...

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

...We have a lot of workgroup members and we've got about 12 minutes left, so let's – we'll just be really concise and we'll catalog the issues and come back to them.

**W**

I had just one comment...

**Jan Oldenburg – Aetna – Vice President, Patient Engagement**

This is Jan Oldenburg.

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

I think I heard Ann trying to say something.

**Jan Oldenburg – Aetna – Vice President, Patient Engagement**

Jan. Jan Oldenburg. I just wanted to pick up on something that Lygeia mentioned, and it is about the whole reconciling of data across provider input. I think the view, download, transmit is a wonderful step forward, but now we have consumers who have data from multiple sources that they are trying to reconcile themselves without tools, without necessarily an understanding of why they're different. And thinking about how we can provide not just the reconciliation tools, but some ways of facilitating for consumers the ability to view their data across provider organizations, to get a lifetime view, I think will be a really important next step.

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

Great. Thank you.

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

This is Cynthia.

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

Hi, Cynthia.

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

Hi. So I want to make three quick points, and I will be quick. One, I want to endorse the person-centered view as opposed to focusing specifically on patient. As Mary Jo acknowledged, the notion of person-centered is kind of difficult and needs some work, but I think that is the direction to go, and reinforces what Rita was saying about the salience and talking about people's situations outside of healthcare. The second thing is that I think we need to have on the table the fact that a lot of the electronic information that we currently have access to online is very static, and that's very much out of step with people's expectations in technology and other places in their lives. So if I think, for example, of what my health insurance gives me now, it's a very static view of an EOB, and I think that really needs to be on the table to be addressed.

And the third thing is, as I think from a policy perspective, we need to still keep urban/rural issues on the table. Because yesterday I was at a meeting where we were talking about rural seniors in Georgia who don't have any telecommunications access at all, in part financial, though they sometimes can't even pay their landline bills every month. So again from a divide perspective, I'd like to keep urban/rural on the agenda.

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

Thank you.

## W

This is ...

### **Korey Capozza, MPH – HealthInsight – Consumer Engagement Director**

Hi, this is Korey Capozza from HealthInsight.

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

Korey.

### **Korey Capozza, MPH – HealthInsight – Consumer Engagement Director**

I just had a – hi, and I came on late, I apologize. I just wanted to echo the comments made earlier about health literacy. I just think it's – we really need to put some attention there if any of these pieces are going to fall into place. I've had occasion with our work through our REC program in Utah to see some of the clinical visit summaries coming out of some of our practice's EMRs and they're really not intelligible to even a sophisticated patient. And so if we're going to get to patients being able to correct their data or take action on their data, that needs to be vastly improved, I think. And I'm not quite sure what the policy avenue is, but it's really a formative step that needs to happen. Thank you.

### **Katherine Kim, MPH, MBA – San Francisco State University – Health Equity Institute Professor in Residence**

This is Kathy Kim.

### **Casey Quinlan – Mighty Casey Media, LLC – Chief Message Officer**

This is Casey Quinlan, who's going to weigh in with another access-related issue. What about uninsured people and...creating an ease of access for them when, depending on – in other words, they don't have an insurance provider to help streamline some of the process of getting data. And then the health literacy thing I think we should be starting in kindergarten, but I'll stop now.

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

Okay, thank you.

### **Katherine Kim, MPH, MBA – San Francisco State University – Health Equity Institute Professor in Residence**

This is Kathy Kim.

### **Ryan Witt – H4Y Corp**

One thing real quick – this is Ryan again, is I mentioned this in the comments that there are companies that for profit reconcile data for payers and for healthcare providers. If there was some way to say, if you guys are reconciling data about a patient, you have to provide that reconciled data to that patient, or something of this sort, there are models within the industry that are being done that where you're reconciling data between hospitals and between different EHRs, that that might help.

## M

Hi...

### **Patricia MacTaggart, MBA, MMA – Lead Research Scientist/Associate Professorial Lecturer – George Washington University**

Hi, this is Patricia MacTaggart, can I ...?

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

Yeah, go ahead Patricia.

### **Patricia MacTaggart, MBA, MMA – Lead Research Scientist/Associate Professorial Lecturer – George Washington University**

Okay, really quick. Two things that build off what's already been said. And one is, the data sources that we're talking about for healthcare, of what is accessible. We haven't really spent much time, even historically, talking about what data sources we're talking about. And then the second thing that I think is – important it's not just about ...

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

Pat, are you there, are – did we ready to lose you? Okay, did we lose the call, is everybody there?

**Multiple responders**

No, we're here. I'm here.

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

All right. Good, I had a panic attack. All right.

**Clarke Ross, DPA – National Quality Forum**

This is Clarke Ross, can I ...?

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

Back with Patricia, but, and I'd like to ask ONC, we're going to go to Clarke in one second, but I want to ask ONC, I think we have a lot of people trying to speak and so if we can think about a way that we can also let people feed some of their comments in after the call, that would be helpful. Go ahead Clarke.

**Clarke Ross, DPA – National Quality Forum**

Thank you. This is consistent with many of the other points, we have a lot of exciting new service delivery initiatives like health medical homes and participant-directed home community based services and Medicaid. And what these have in common are multiple providers and generally non-medical providers and if we could have a plan, strategy to integrate Health IT around the concepts we're talking about in the up-front stage of these service delivery initiatives, many of which are already out the door, I think that would be a good contribution.

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

Thanks Clarke.

**Mark Savage, JD – Consumers Union of United States, Inc.**

This is Mark Savage, if it's okay.

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

Mark Savage.

**Mark Savage, JD – Consumers Union of United States, Inc.**

The various comments raise the question for me, how does ONC decide to stack the different activities that it's doing. So for example, some might say we need to get some systems up and running and then we can focus on health literacy, others might say, if we don't build the health literacy in at the beginning, the systems that we hope people will use, won't be used and so it affects the uptick. So, I don't, I don't have comments yet on what a correct order might be, but instead I'm interested in hearing from ONC about how they approach that question, how they decide how to stack the things?

**Lygeia Ricciardi – Office of the National Coordinatory**

I'm just going to answer that real quick, which is to say, I think you can't just sequence things, you have to – I mean, like our three As slide that I was sharing Mark, this is Lygeia, shows that we're basically trying to hit all pieces of access, action ability and changing attitudes at once, because you can't do them sequentially. Even though we can put greater emphasis, we at ONC, for example, put greater emphasis on the access piece, because that's the greater lever that we have. Really the other pieces are important and we need to get them under way. The other point I'll make is that it's not just work that ONC does but if we articulate a need for somebody to take action, we are empowered, as ONC and as this group, to suggest, hey, we need some other agency or other actor or stakeholder to take some action. So it's not just limited to us.

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

Thanks Lygeia. Somebody was trying to ask a question right before Mark.

**Katherine Kim, MPH, MBA – San Francisco State University – Health Equity Institute Professor in Residence**

Yeah, this is Kathy Kim.

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

Hi, Kathy.

**Katherine Kim, MPH, MBA – San Francisco State University – Health Equity Institute Professor in Residence**

Hi. Well the – this is a great segue because the question that I wanted to ask was around the – was not just the sequencing issue, but really where we find the resources to do all of these things in concert that we need to. And it seems to me that what we don't have is sort of this organizing framework for technology-enabled engagement, where we're thinking about the issues of digital divide and disparities and prevention and chronic disease management and all of these things at the same time. And yet we have multiple things happening in the environment that are each individually having a roadblock. So, it might be it broadband access, it might be access to devices, it might be availability of data, it might be health literacy. And it would be great to see coming out of this group maybe a framework that say, here are all of those issues, here are the agencies that work on those issues and then the technology that needs – I'm sorry, the policy that needs to get sort of reconciled across those agencies, we might actually identify some of the gaps that are really having a major impact on engagement.

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

So Lygeia, I don't know if you want to respond to that, because I do think you guys have done a fair amount of that, is that right. Between your various strategic plans and the consumer strategies.

**Lygeia Ricciardi – Office of the National Coordinatory**

We have done some, but I think we're, I mean, honestly our consumer program at ONC is not very old, and we have done some fairly intense work with a couple of other agencies. But I think that we do need to do new work, whether with this group or otherwise, in thinking more broadly about roles of different agencies and how they interrelate and how we could better partner with, for example, the FCC and others to coordinate some.

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

Great. So the other thing I want to do in the last just – we've got about two minutes. But one of our – I think we've done a good job looking at the questions on the screen, talking about some pressing policy issues, particularly around reconciliation, correction, blah, blah, blah. I think that clearly falls in the pressing and the gap category. The other piece though that I want to think about is areas where if we did some work it would really accelerate impact. And we talked on the last call about the idea of a shared care plan, and it's been proposed, largely for Stage 4, because I think even though we do have things like CDA, etcetera, I'm not sure that people think the policies are there. Because we struggle with things like who owns it, who grants access to share it, how is it useable for different individuals. What the Meaningful Use Workgroup has talked about is moving away from the idea that a care plan is some kind of a static document, and moving toward this notion of more of a collaborative platform where both provider, consumer, patient, family member can go back and forth. And so I do think that if we were able to take on some of those tricky questions, that could potentially accelerate our ability to do a more robust shared care approach, sooner rather than later. Any reactions to that, or thoughts on other areas that would be similar?

**Clarke Ross, DPA – National Quality Forum**

This is Clarke. Amen to collaborative thought forum and shared person-centered planning.

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

Thank you Clarke. Hallelujah.

**Jan Oldenburg – Aetna – Vice President, Patient Engagement**

I would agree with that as one of the key areas, give that it is one of the places where there's an opportunity to use the trusted relationship between providers and patients, I'm going to use the word, to motivate to action. And so that idea that it is a shared partnership around what actions to take makes a lot of sense as a place to transform that relationship. And this is Jan Oldenburg.

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

Thanks Jan.

**Ann B. Waldo, JD – Wittie, Letsche & Waldo LLP**

This is Ann Waldo. I have one quick thought. It's not so much on the shared care plan, but perhaps something that might have some more immediate impact as we work toward things like the shared care plan. I would love to see us do some work to identify areas of confusion today that serve to frustrate consumer empowerment and block access to records and more broadly, block the VDT CC, which I'm hearing about for the first time, and I think sounds great, and really then impede care. And I think we could benefit from getting very specific. I find there's tremendous ignorance out there among providers about the new electronic access rights, as well as an enormous amount of overly conservative legal interpretations about access and providers and entrepreneurs that believe that texting is illegal under HIPAA and so on. So at – last week, there were conversations among entrepreneurs and amongst some ONC folks, about how we could get very specific about trying to identify questions, get some FAQs, hopefully get them put out there by HHS and widely disseminated so that people are able to take advantage of what is already available for them under existing law. And I would love to help that, I've been interested in it for a long time.

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

Thanks Ann. All right. So we're at the witching hour. So, ONC folks, how should folks best go about sharing any additional thoughts they have at this point?

**Erin Poetter Siminerio, MPH – Office of the National Coordinator**

Christine, this is Erin. I can offer I'll send an email to the group afterwards with the health affairs paper and if folks have additional comments they just didn't have time to state on the phone, I'll be collect those, aggregate them, reconcile them and get them out to the group.

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

That would be great. So folks, go ahead and just respond only to Erin, so we don't clog everybody's inboxes and then she'll turn them around. What I'd suggest is, we'll take those, I'll work with ONC and Leslie Kelly Hall from the Technology Workgroup and we'll think through what a sequence could look like. And I also want to think it through in a way that leverages the strength of this group and recognizes the hand-offs where we may be able to hand something off to another agency or another workgroup, to get them working on it, so that it's not just us taking on everything. Any last comments before we close? Okay great. Thanks everybody for another jam-packed call, and we will talk to you soon.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

So, we'll just open it up Christine for public comment before we go.

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

Oh, I forgot, MacKenzie. I'm sorry.

**Public Comment**

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

It's okay. Operator, can you please open the line for public comment?

**Rebecca Armendariz – 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. No comment at this time.

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

All right, thanks everybody.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thanks everybody.