

**HIT Standards Committee  
Consumer Technology Workgroup  
Transcript  
April 18, 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 Standards Committee's Consumer Technology Workgroup. This is a public call and there is time for public comment built into the agenda and the call is also being recorded so please make sure you identify yourself when speaking. I'll now go through the roll call. Leslie Kelly Hall?

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

Present.

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

Thanks, Leslie. Brian Ahier?

**Brian Ahier – Gorge Health Connect, Inc. – President**

Present.

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

Thanks, Brian. Christine Bechtel? Brian Carter?

**Brian Carter – Cerner Corporation – Executive Strategist**

Present.

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

Thanks, Brian. AJ Chen? John Derr? Tonya Dorsey? Arthur Henderson?

**Arthur Henderson – Affinity Networks, Inc. – President**

Present.

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

Thanks, Arthur. Susan Hull? Susan, are you on the line?

**Susan Hull, MSN, RN – WellSpring Consulting – Chief Executive Officer**

Present.

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

Thanks. Liz Johnson?

**Elizabeth Johnson, MS, FHIMS, CPHIMS, RN-BC – Tenet Healthcare Corporation – Vice President,  
Applied Clinical Informatics**

I'm here.

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

Thanks, Liz. Tom Jones? Mo Kaushal? Russ Leftwich?

**Russell Leftwich, MD – Tennessee Office of eHealth Initiatives – Chief Medical Informatics Officer**  
Present.

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

Thanks, Russ. Holly Miller? Sally Okun?

**Sally Okun, RN, MMHS – PatientsLikeMe – Vice President, Advocacy, Policy & Patient Safety**  
Here.

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

Yair Rajwan?

**Yair Rajwan, DSc, MSc CS, MSc HIS, PFNLM – Visual Science Informatics, LLC – Director, Analytics Visualization**

Good morning everyone.

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

Thanks, Yair. John Ritter?

**John Ritter, MS – EHR Workgroup and Volunteer HL7 – Co-Chair, Software Engineer**

Yes, John's here.

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

Thanks, John. Anshuman Sharma? Fred Trotter? Kim Nazi?

**Kim Nazi, PhD, FACHE – Veterans Health Administration – Management Analyst**

Good morning.

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

Thanks, Kim. Susan Woods? And any ONC staff members that are on the line if you could please identify yourself?

**Mary Jo Deering, PhD – Office of the National Coordinator – Senior Policy Advisor, Office of Policy & Planning**

Mary Jo Deering.

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

Thanks, Mary Jo.

**Tonya Dorsey – Blue Cross & Blue Shield of South Carolina – Chief Implementation Architect**

This is Tonya Dorsey. Sorry, I joined late.

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

Thanks, Tonya. Okay with that I'll turn the agenda to you Leslie.

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

Thank you, and I'll apologize in advance if you hear background noise. I'm at the Meaningful Use 2 meeting. Do we hear the static or is that just me hearing that static? There we go. I'm in the Meaningful Use 2 meeting in Washington, D.C. So, thank you all for joining. Today we're going to spend some time in review and we can go ahead to the next slide on the agenda and get a few updates. So, we're still in that centering phase making sure that all of us are brought up to speed on what's going on today with patient engagement standards.

During our work together I will ask you at times to lead efforts to help to harmonize efforts or inform efforts that each of us are working on. So, the work that we do as a committee and individually in many committees that we are on will all help to move the patient engagement agenda. So, today we are going to hear from ONC about the consumer activities going on. We're also going to continue with our introductions of the team members who did not get a chance to speak talk about developing a standards inventory that support Meaningful Use 2, 3 beyond and patient engagement and do some next steps, which will include some homework over the next month.

So, with that I will first turn it to Mary Jo Deering and I also want to let folks know that Erin Poetter will be joining and she might be interrupting Mary Jo at some point, she is going to present activities on the Blue Button Project and it's right now being presented at TEDMED so we want to be sensitive to her time. And, so I'll turn it over to Mary Jo and we can switch slides and talk about what's happening today at ONC.

**Mary Jo Deering, PhD – Office of the National Coordinator – Senior Policy Advisor, Office of Policy & Planning**

Thank you very much Leslie, I appreciate the opportunity to be here. ONC really is committed to consumer engagement, patient's engagement through consumer e-Health, you may know in our published health information exchange strategy we have three pillars to that strategy one is directed exchange, one is a query-based exchange and the third is consumer mediated exchange. So, our leadership and the entire office is very committed to pursuing this path.

So, these are some of the activities that we're going to tell you about today. Erin is actually going to talk about the consumer engagement strategy and the Blue Button and she has a separate deck of slides so when she joins we'll go to that. So, I'm going to ask the operator to jump to the, probably down two slides. There you go, thank you very much.

So, this is the first activity, some of you may know that we published a strategic plan a couple of years ago and it had an entire section on consumer engagement. We don't want the strategic plan to be a static document, we want it to be a living document and so we are experimenting with new ways to get really interactive feedback on how to keep it alive and move onto a next iteration.

So, right now we are working with Cornell University, which has a very innovative on-line comment tool called Planning Room and we've put up some new text about consumer engagement and we're asking the public's input on it, it includes information about our three As strategy, Access, Action and Attitudes, that Erin is going to tell you about and we're also going to ask for input on some emerging issues like identifying useful health information, useful to both patients and providers, patient generated health data which I'm going to talk about in a minute, supporting shared decision making through Health IT, decreasing health disparities, supporting personalized health care which is an emerging model and supporting the new health care delivery and payment models, and then finally using Health IT to enable research and inform practice through things like the patient centered outcomes research project.

The public comment period closes on May 9<sup>th</sup> and at the end of the call today there is going to be a URL to remind you how to go and offer comments in your individual capacity not as an official Workgroup member. Next slide.

So, on patient generated health ONC does believe very strongly that there is a significance of progress in improving health and care that can occur when the patient's own data created by the patient and contributed by the patient is effectively, you know, integrated and so we asked our cooperative agreement partner, the National eHealth Collaborative, to convene what's called a Technical Expert Panel to provide input on how to successfully implement patient generated health data, some of you may know that providers get appropriately, you know, concerned, they have an image of a fire hose of data coming at them and they are legally liable in many instances and so we're trying to come up with some first steps that can help set some guardrails.

So, as you can see, the goal was to identify use cases and best practices for how to integrate this data into a flow and specifically we wanted to support the recommendations for Stage 3 Meaningful Use. Next slide.

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

Can I just ask people to please mute your lines if you're not actively speaking we're getting a lot of noise in the background, thanks, and Erin has joined the call I believe.

**Mary Jo Deering, PhD – Office of the National Coordinator – Senior Policy Advisor, Office of Policy & Planning**

Okay, Erin, I tell you what I'm going to go really – the next two slides and then I'll hand it over the Erin. So, the first Meaningful Use objective specifically relating to patient generated health data you can read on the slide there and it does specifically call for the use of what is sometimes called PGHD to improve patient care and engagement and so our TEP is looking at how this could be accomplished. The next slide please?

These are two additional objectives that we think relate to patient generated health data, important opportunity for patients to take a look at their record which they will do now under view and download, and transmit, and offer corrections or additions and then there is also a proposed objective about improving electronic messaging and we think that electronic messaging is obviously a channel for patients to submit data in a variety of context.

And, so the TEP is going to do an additional set of – we don't call them formal recommendations, but an outline of best practices or promising that can encompass all of these three proposed objectives to help sort of buttress the case for including them. I will stop there. I have some more to talk about afterward, but let's hand it over to Erin now.

**Erin Poetter Siminerio, MPH – Office of the National Coordinator – Policy Analyst, Office of Consumer eHealth**

Hi, can folks hear me okay?

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

Yeah, we can hear you. Thanks, Erin.

**Erin Poetter Siminerio, MPH – Office of the National Coordinator – Policy Analyst, Office of Consumer eHealth**

Great, okay. So, unfortunately, I'm not in a position to pull up the deck but hopefully I can just – I'm going to be kind of walking through these slides. So, first of all I just want to say thanks for giving us an opportunity and we're thrilled to see this group come together and start its work. So, we thought it would useful to give you a very high level kind of 50,000 foot view of our Consumer e-Health Program at ONC and our three A's strategy, and sort of what we have set out to accomplish over the next couple of years.

And if you go to the first slide we published, earlier this year, a paper in the Health Affairs called the National Action Plan to support consumer engagement via e-Health and we do have the rights to...I can send around a link to the PDF after the call for folks, but that's a great reference to sort of what I'm going to talk about today which is our three part strategy for really advancing consumer engagement via e-Health and to start the evidence-base for supporting consumer engagement is growing, there has been a lot of great work by Judy Hibbard and others that have demonstrated that activated patients get better outcomes.

And we believe technology is a really powerful tool to enable patients to do a number of things like engaging in reviewing their information to make sure it's correct, serving as a health information exchange of one and being able to mediate where their information goes so that they can make sure that the right information is available at the right time in the absence of true interoperability which we're certainly on the path toward but is not a reality today for most places.

And then finally that these tools and technologies can enable patients to better understand their conditions and to leverage these tools to make meaningful change in the way they're managing their own health but then also to support them in managing the health of loved ones. So, there is a great case I think for consumer engagement which we've laid out in the paper, but what I really want to focus on today is our three A's strategy for advancing greater consumer access to data, use of tools and technologies to make that data and that information more meaningful and actionable so that it does actually lead to behavior change, and finally shifting attitudes around the traditional kind of mindset of the role of the patient and a provider so that it's much more participatory and much more of a two-way kind of slow and exchange of information and shared decision making.

So, on the next slide there is sort of an overview of what we're doing in these three areas, so I'll just kind of dive into each of the three A's in a little bit more detail to talk specifically about some of the activities that we have underway. So, in the access bucket our efforts to increase access to information or just simply to make it easier for patients to exercise their legal rights to get a copy of their health information to review that information and to request and then enter the information as inaccurate or incomplete.

We have HIPAA, which I'm sure you are all familiar with, which the modifications for HIPAA go into effect later this year, which support patients getting access to their information in the electronic copy if it's available that way, and HIPAA is very misunderstood, we have fortunately the Office for Civil Rights has really stepped up its enforcement activities in this area and actually accessed large fines to institutions who have denied patients access to their data.

So, we've been partnering with the Office for Civil Rights, they're doing a large campaign called the Rights to Access Campaign to educate Americans about their legal rights and to empower them with things like a memo that appears on our website and on their website that patients can download and take into the doctor's office that clearly explains that they do have a right to this information, because HIPAA as we know is a valve, it's not a blockage its intended to make it easier for patients to exercise that right. So, in coordination with the folks in that office we're doing a lot of work to educate Americans about that right.

Our biggest lever as you all know is Meaningful Use Stage 2 and specifically the provision to enable patients with a way to view, download and transmit their health information to a third-party, so those requirements go into effect later this year for hospitals and then starting next year for eligible providers, and those requirements are really critical because they're going to enable this information that's been silo'd and locked in EHRs to come out into the patients control and into the patient's hands.

And so, what we've been doing to make it easier for institutions to adopt these new standards to facilitate an easy way for patients to get that information is our work on Blue Button+ and I think before I dive kind of deeper into what is Blue Button+ I want to just kind of explain at a high level what is Blue Button versus what is Blue Button+, because I think there's been a little bit of a misunderstanding about kind of what's distinct about those two terms.

So, for folks who aren't familiar with Blue Button it started or originated at the VA in 2010 and it was simply a way for beneficiaries to log into the My HealtheVet portal click a Blue Button and download a simple text file of their health information and it was intended to solve the problem of those beneficiaries seeking care outside the system and kind of having the information that they need to better coordinate care outside the system.

So, fast forward to today, it started at the VA, CMS has adopted Blue Button since and now Medicare beneficiaries can download part I believe it's A, B and D data, I actually did this yesterday for my father, so I can assure you that it works, it's pretty exciting, log into MyMedicare.gov click the button and then you've got a list of your providers, a list of, you know, MEs, sort of diagnoses codes and other information that's really critical to have in the palm of your hand.

So, in the action bucket, as I mentioned, we're doing a lot of work to make it easier for these institutions to meet Blue Button+, so Blue Button is simply a way for patients to get easy electronic access to their health records. There aren't necessarily any standards for it, although at a minimum Blue Button means you can at least download. So, view only on a patient portal is not Blue Button, but being able to view that information and download it and get it into your control is Blue Button.

Now, Blue Button+ is more specific and it again meets and builds off of Stage 2 Meaningful Use requirements for view, download and transmit. So, in its simpler sense it's actually the implementation guide for view, download and transmit. And the reason why we worked very closely with a number of volunteer organizations, I believe there were 68 total, who were convened through the standards and interoperability framework to solve this problem is that we hosted a summit at the White House about a year ago and at the summit we asked a simple question to leaders and a variety of them said, what is the...what's needed to unblock data liberation and what's needed to really turbo-charge patient access to data?

And what they said is we need an easy way for consumers to receive an automatic update or an automatic feed like an RSS type feed of their information anytime something changes. So, the ability for patients to set it and forget it so that any time there is a change that information flows automatically. So, coming out of that effort we formed the Standards and Interoperability Auto Blue Button Group, which culminated in February of this year in the publication of this implementation guide for doing Blue Button+.

And again, you know, I think far too many consumer tools have failed because of the reliance on patient's self-entering in data, Google Health being the most I think recognized example of that. So, Blue Button+ really fixes that problem and is a way for your health records to be securely transmitted from an EHR to your application of choice whether that's a personal health record or whether that's another application and it really puts patients in control of where their information goes.

So, again there is an implementation guide, I'm not a technical expert so probably not the right person to field questions about the specifics of the guide, but I can point you to [bluebuttonplus.org](http://bluebuttonplus.org) where there exists an implementation guide for developers on how to build tools that can consume this data and also an implementation guide for data holders that again meets and builds off of the view, download, transmit requirements for meaningful use.

So, what we're really focused on at the moment is trying to encourage more institutions to adopt these standards and to make Blue Button+ available and we're also working on driving adoption of Blue Button+ in the data holder institutions but at the same time working on the receivers to make sure that there are aggregators that can take this data from multiple sources, aggregate it, reconcile it and then ultimately enable patients with the way to not only get their data all in one place but be able to send that information to providers to facilitate care coordination, that's the piece I think where your work is really going to help in terms of facilitating that patient to provider exchange of information. So, a lot of work that needs to be done there.

In the action bucket another sort of lever we have to again advance making it easier for patients to use their information is through developer challenges and we've run a number of these throughout the years most recently the Blue Button mash up challenge where we issued a challenge to developers to develop a tool that mashed up the Blue Button downloaded data with other types of data, to again, take that data and make it more meaningful and what came out of that was three applications that are available today for consumers who do have access to Blue Button to again download their information, upload it into these tools and start to better understand their health records.

Another challenge was the health records design challenge where we sought to kind of solve the problem that health records are sort of difficult to understand and not visually very appealing for the most part and so we challenged designers across the community to contribute their ideas for making the record more beautiful and more meaningful, and we now have awarded winners, and those folks are going to be open sourcing the code for the winning application.

So, that's very exciting, any EHR technology company can take that open source code and integrate it into their products, so again make it easier for consumers to understand and interact with their health information, so that's pretty exciting to see.

And then finally in the action bucket, before we move to attitudes, I want to mention that the office, OPP, did a lot of work in coordination with FTC on the development of a PHR model privacy notice that vendors can use to communicate their data sharing and security policies to consumers in a very uniform and easy to understand way. So, this was modeled after the nutrition...label and again is just a tool that can help consumers compare different PHR products against each other.

So, finally, in the attitudes bucket we are doing a lot of work, this is probably the most challenging yet important work that we are doing, we're doing a number of things to try to shift attitudes and frequency of notions about the role of patients and providers and their care. And we're really relying on the power of storytelling for the most part to really kind of I think facts are important, science is important, but stories are much more powerful.

So, we've – on healthit.gov we've profiled a number of really powerful moving patient stories of the impact that getting access to information, having tools, being a more engaged patient is really playing in people's lives. So, there are a number of resources on our website that are again are aiming at telling that emotional story.

And then we're also – we also developed an animated video which is a three-minute sort of overview for all Americans, an easy explanation that's both informative and entertaining that explains the benefits of getting electronic access to information and being an empowered patient and that's also available on our website and is available for other organizations to take and embed on their sites to tell that powerful story.

So, that is a very high level overview of kind of what we're doing in each of those three areas it doesn't cover the complete waterfront but I think it's a good sort of sampling of some of the activities that we have underway.

And, I just also want to mention there is one other initiative that really doesn't fit very nicely into any of the three buckets, it sort of compliments our work in all three and that is our Blue Button Pledge Program, which was started in September 2011 when we kicked off the program and it's really a way for organizations or entities to show their support for patients getting access to and using their health data.

So, there are two types of pledges you can make, you can either be a data holder in your institution to have data who pledge to make it easier for consumers to access that information and then non-data holders, which is everyone else who wants to be supportive, wants to drive forward this change and is committed to doing that through their outreach and educational activities and efforts and we're using that group to...as sort of a convening to learn best practices from that group to sort of figure out exactly what else needs to be done.

And so on a regular basis we do bring these folks together at events through webinars and other mechanisms to again help inform this work and help really advance the adoption of Blue Button and the education and outreach that is needed to communicate the value of this to Americans.

So, with that I will stop talking and I'm happy to answer any questions, but again, I would point all of you to the Health Affairs article that was published earlier this year since it does go into a little bit more detail about the strategy and what we've set out to do.

#### **Leslie Kelly Hall – Healthwise – Senior Vice President, Policy**

Super, thank you, Erin. Are there any questions of the group? I know that some of you have been involved in some of these initiatives as well; if you have any comments to make as well we would appreciate that.

#### **Kim Nazi, PhD, FACHE – Veterans Health Administration – Management Analyst**

Well, this is Kim Nazi and thank you very much for a wonderful overview it feels like nothing short of joy to see everything evolve from that first meeting in January 2010 to now. There are so many overlaps with a lot of the work that VA continues to do, so, I know that we're going to circle back to do kind of the member updates; I'm happy to say those things now or then, maybe then would be better.

I just want to make a couple of points now, one is that, you know, I'll tell you then that VA is also working down that trajectory for not just view and download but also transmit so I can tell you a little bit about that when we get to kind of the member updates. One thing that strikes me in terms of the set and forget, and it comes based on our experience with thinking about this cycle of data refresh if you will, is that it really needs to be kind of a nuanced approach so we're not – so that we're careful to be sure that the right people have the most up-to-date data at the right time, but also giving consideration to have that kind of refresh cycle happen so that there is not, you know, streams of data that isn't being used effectively as well. So, I think, there is a nuance there that warrants really thinking through.

The only other comment I want to make is to also give a shout out to DoD who also joined VA and CMS early on in the Blue Button effort and today offers TRICARE online beneficiaries a Blue Button product as well. So, thank you very much.

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

And Kim, I think we're in the millions of uses are we not?

**Kim Nazi, PhD, FACHE – Veterans Health Administration – Management Analyst**

Yes, we are, we are.

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

Yes, yes, that's great. All right any other questions for Erin, otherwise we'll let her go back to TEDMED.

**Arthur Henderson – Affinity Networks, Inc. – President**

Erin, this is Arthur Henderson with Affinity Networks.

**Erin Poetter Siminerio, MPH – Office of the National Coordinator – Policy Analyst, Office of Consumer eHealth**

Hi.

**Arthur Henderson – Affinity Networks, Inc. – President**

A couple of things, first thanks for the introduction on that. I wished I'd known you a year ago and gotten that introduction. We've actually helped a Blue Button product that supports the VA right now so I'd be interested in providing more information on that. But, is there any calendar on the implementation of Blue Button+?

**Erin Poetter Siminerio, MPH – Office of the National Coordinator – Policy Analyst, Office of Consumer eHealth**

So, in terms of the timeline, I mean, we would love for organizations to implement it right away, you know, the guide is ready. We have – so in February of this year we had five demos at HIMSS of actual Blue Button+ demonstrations between providers and receivers. So, we have demonstrated that the implementation guide works and now those early adopters, those five institutions are on the path towards actually making that a reality for their patients and their institutions.

So, one of the things in the near term that we are planning to do is to reconvene a group, the same – a similar group that we had at the first patient access summit last year to bring those folks back together since again, they told us, you know, we need...here's a problem that we think needs to be solved and the solution was the Blue Button+ implementation guide.

So, we want to bring those folks back together and say we've built it and now we want you to come and we want more people to come, so there is an early...a group of early adopters but we hope that, you know, all institutions that are on the path to Meaningful Use will adopt these standards.

Now, I want to be clear that the requirement for Blue Button+ do go above and beyond what is required in the Meaningful Use Stage 2 rule, but the additional effort that's involved, what we've heard from the folks who have implemented is that it's pretty minimal. So, again, you know, our goal is to have all institutions adopt this as they're working towards meeting Stage 2 and for hospitals they'll start to do that in October of this year and for eligible providers in the beginning of next year.

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

So, Erin, this is Leslie again and I think it would be worthwhile and maybe Mary Jo we can get an addenda item for our next meeting which goes into the technical detail, because I do think that Blue Button+ will be foundational to any work that we might do and a clear understanding of that will be important.

**Erin Poetter Siminerio, MPH – Office of the National Coordinator – Policy Analyst, Office of Consumer eHealth**

Great point. So, I can certainly work with Pierce Graham-Jones and Ryan Panchadsaram who are leading up the development of that to get them on the next call, absolutely.

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

Thanks Erin.

**Arthur Henderson – Affinity Networks, Inc. – President**

And Erin, I'm also at TEDMED I'm going to send you an e-mail, hopefully we can connect sometime today.

**Erin Poetter Siminerio, MPH – Office of the National Coordinator – Policy Analyst, Office of Consumer eHealth**

Great, okay.

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

I will be at the reception, this is Leslie, tonight at TEDMED at Kaiser if anyone is there please let's also say hi to each other. Okay, super and then we'll turn it back to Mary Jo. Thank you, so much Erin.

**Erin Poetter Siminerio, MPH – Office of the National Coordinator – Policy Analyst, Office of Consumer eHealth**

You bet.

**Mary Jo Deering, PhD – Office of the National Coordinator – Senior Policy Advisor, Office of Policy & Planning**

Thanks, very much, okay so this is the quick change that is here, next slide, go to the next slide please. As I mentioned just to wrap up on our work with patient generated health data these are sort of the components that we envision will be in this final report from the Technical Expert Panel it's, you know, promising practices as I've said, because patient generated health data is still too new to formally label anything a best practice.

And we'll talk about what organizations need to do to prepare to receive patient generated health data and how they need to prepare their patients, what data is perceived to be of key value to both providers and patients for, you know, a first step in this direction.

And finally, processing workflow issues about patient generated health data that can really ensure that it's not overlooked, that it's appropriately integrated and it also includes workflow for the patients so that expectations on both sides, the patients and the providers are sort of mutually they're synced up and everyone knows exactly what data can be submitted and how it will be used and we hope that those guardrails will make it much easier for this to really get off the ground. Next slide, please.

Okay, now so we've talked about some things that are very much either in the hearing now or in the near-term. I'm in the Office of Policy and Planning in ONC not the Office of Consumer e-Health and we do not only general policy related work but we also do oversee strategic planning and we are charged with, you know, looking sort of out at the far horizon.

So, this next project we called the person at the center and this is to begin to identify what we recognize is probably a vision for 2020 at the earliest understanding the difficulties of changing personal and organizational and institutional, and cultural behaviors, but as you can see here we have a pretty powerful vision where each individual, you know, can be active in managing their health and partnering in their health care using HIT.

So, this vision and some preliminary work was tuned up, shall we say, by a different kind of a panel that we had convened, and I think some of you were probably on that, to help us begin to firm up this vision and take some steps toward how it might be accomplished. So, the next slide, please.

So, the core of this vision is to focus across the spectrum of wellness and healthcare. Next slide, quickly. So, the left-hand side although it's labeled wellness it really does encompass all of the things that go into not just prevention and wellness activity but also the self-management of conditions because we certainly hope that over time chronic conditions can be managed in many cases they're managed even without the assistance of a provider or you only see the provider every 5 years so you're virtually on your own. So, on one side we really want to strengthen the policies and programs and tools that can help individuals be more active in not only their self-prevention activities but their self-management of conditions. Next slide, please.

Then we envisioned this sort of middle area where as we all know interactions with the healthcare system have pretty rough edges right now and we want to make it much easier for people to move between these two spheres including, you know, some very basic things like, you know, facilitating on-line scheduling and e-mail communication with the doctors so that you know when you really do need to get in, so a whole variety of activities that can help make that middle ground a little smoother. Next slide, please.

And then when you are ill and when you are in a patient relationship we strongly support shared management, shared decision making. We know that many conditions are in fact explicitly preference, the treatments are preference sensitive and so we want to make sure that across the range of illness conditions that this is a shared management and a partnering relationship. Next slide, please.

So, one of the things that we need to do is then begin to draft some building blocks how do you get to this vision, what's going to be needed in the areas of policies, research, programs to enable this to...on both sides on the sides of the patients, the consumers, you know, their lay caregivers and their providers. And so we're now going to be firming up the notion of these building blocks and we want them to be really game changing, we'd like them to be broad reaching, we'd like them to support behavior change not just on the part of individuals as consumers and patients, but behavior change at the professional level and also behavior change of institutions because we know that institutional behaviors are just as addictive as personal behaviors and of course using Health IT and information sharing can make this possible.

So, we'll be firming up or beginning to develop, I shouldn't say firming up, but we'll be developing these building blocks over the next several months and you'll hear more from us, but this just lets you know that we are very eager to support and embrace not only activities that can move us forward over the next 2 to 3 to 4 years but really into the future when we really hope that this new vision will be not a vision but a rule. I believe that's my last slide, let's see, yes, that was my last slide. Thank you, very much and I'm happy to take questions, Leslie.

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

Yeah, that would be great I know you went through a lot but much of our work will be either informed by this vision or supporting the vision, in addition we will also be working on gaps in standards that are needed to be filled in order to fulfill the vision and to fulfill the work efforts that we mentioned earlier. Are there any questions of Mary Jo or the other ONC staff from the team?

**Brian Ahier – Gorge Health Connect, Inc. – President**

This is Brian Ahier, thanks Mary Jo, appreciate the update. I just wanted everyone to – if you haven't already seen it to be aware of a white paper from last year on patient generated health data that I think is really helpful in sort of framing this issue and, you know, it's a bit meaty, so, you know, take your time and if you haven't had a chance to read it yet I'd recommend it to the committee, thanks.

**Mary Jo Deering, PhD – Office of the National Coordinator – Senior Policy Advisor, Office of Policy & Planning**

Well, thanks, Brian, that's an excellent suggestion and I'm happy to send a link to both that paper and to the hearing that was held on patient generated health data, we're definitely building on all of that super work from 2012 in the TEP as it moves forward. So, thanks for reminding me about that.

**Brian Ahier – Gorge Health Connect, Inc. – President**

Yeah, I just e-mailed it out to everyone on the Workgroup.

**Mary Jo Deering, PhD – Office of the National Coordinator – Senior Policy Advisor, Office of Policy & Planning**

Perfect.

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

Anything else? Any other questions from the team. All right, so some of – those of you who were not on the call or who did not get a chance to add your comments one of the important things of this work is the fact that we represent so many different areas of standards and policy around the country geographically as well as different standard bodies and so part of our work going forward is to inventory our skill sets and to inventory the work that we're doing along with the work that ONC has laid out to identify gaps, to

identify opportunities for harmonization, opportunities to inform each other and opportunities for leadership of this group and you'll hear those three things brought up from me often.

And so I would invite, I think we have a few folks who have not been able to talk about their efforts, if we could go to the next slide. There is a word table that we just sent and you'll see what we're trying to capture in this first phase and that will be part of your homework assignment is to correct or edit it, or add to that, but please send your information to Mary Jo and we'll give you that e-mail address as well. Next slide, please.

So, what we're looking for in the inventory is to look at the patient engagement Meaningful Use objectives, the standards identified and the gaps and before I talk about that I'm sorry let's go back two slides and get all of those of you who have not been able to identify, I'd like you to talk to or excuse me, say who you are, the objectives that you're working on and standards that you're working on that support patient engagement and the teams that you're involved. Do we have folks on the call that were not able to do that introduction last time?

**Arthur Henderson – Affinity Networks, Inc. – President**

Yes, this is Arthur Henderson with Affinity Networks we've been working in the mobile health space for about 15 years now, first applications written the Apple Newton probably some of you were too young to remember that, but we've done a couple of different clinical trials with mobile technology in the Army around diabetes and most recently we're deploying a product with the Veterans Administration using Blue Button and social media linkages, and tying into provide medication reminders, appointment reminders, support video conferencing between the provider and a patient, all around increasing engagement and I'm really interested in...we're doing a lot of work around redefining engagement, you know, engagement at one point was thought as a binary item, a patient was engaged or not, now it's gone to many degrees of engagement and moving towards personalization of engagement, you know, what is engagement for one person versus another. And, the real goal of all this engagement that we can't lose track of is outcomes. So, regardless of what my percentage of engagement is if my outcome is correct I by definition was engaged.

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

So, Art, what standards are you working on beyond the Blue Button currently?

**Arthur Henderson – Affinity Networks, Inc. – President**

Well, we actually – Blue Button is the main one we're working towards because we started with the VA, we're very interested in implementing Blue Button+ and we've also had some conversations with folks at military health about connecting on that as well. We previously did a lot of stuff on the commercial space with some Blue Cross Blue Shield plans but have found it easier to have successes on the DoD side. We definitely want to work with CMS and do some things in that area as well. So, Blue Button is the main standards we're using but there are a lot of other interfaces we need to make use of as well.

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

Great, thank you. Anyone else who didn't get a chance ...?

**Brian Carter – Cerner Corporation – Executive Strategist**

Hi, this is Brian Carter from Cerner Corporation, and most of you probably know Cerner if you think about that Venn diagram as the right side of that Venn diagram and providing a lot of capabilities in that space. My division of the company is focused on the left side of that Venn diagram and for the last several years we've really been working on building a lot of capabilities for healthcare providers that are in that overlap space to make those interactions more seamless and really over the last couple of years have started to focus on billing out capabilities for the left hand side of that picture as well a lot of self-management tools and things like that.

There are a lot of different standards that we are focusing on Blue Button; one of the members of my team actually sits on one of the workgroups helping pull those standards together. Direct, some of you may know that Cerner has been a large contributing partner to the Direct Project since the inception of it. In addition, adopting the C-CDA standard and I'm trying to think if there are any others that we're focused on right now – those are the big ones that we're really focused on.

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

And I would just like to say thank you and compliment the Cerner team because they are very involved and engaged in Direct as you mentioned, and Blue Button, and I just wanted to say thank you.

**Elizabeth Johnson, MS, FHIMS, CPHIMS, RN-BC – Tenet Healthcare Corporation – Vice President, Applied Clinical Informatics**

Hey, Leslie, this is Liz.

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

Great.

**Elizabeth Johnson, MS, FHIMS, CPHIMS, RN-BC – Tenet Healthcare Corporation – Vice President, Applied Clinical Informatics**

So, I'm from Tenet Healthcare and I would say this is a really great segue because Cerner is our partner in creating the technologies and standards that we will use. We touch several million patients a year and so one of the reasons in working with Leslie that I wanted to be sure that we were at the table and learning and affording our patients the things that we just talked about which is around, you know, we're installing the patient portal from Cerner we're really reaching out and trying to engage patients in their care. So, you know, this is an opportunity for me to better understand what is out there and how to use it in the real world is what I would say. So, thank you, Leslie for pulling this together and helping us make this happen.

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

And Liz is also on the Standards Committee with me and also chairs is it the Implementation Work Team?

**Elizabeth Johnson, MS, FHIMS, CPHIMS, RN-BC – Tenet Healthcare Corporation – Vice President, Applied Clinical Informatics**

Yes.

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

So, very, very much involved in making sure all the standards that we recommend up through helps the Standards Committee can be implemented. So, a very important team that we will probably work with ongoing. Anyone else that didn't get a chance?

**Kim Nazi, PhD, FACHE – Veterans Health Administration – Management Analyst**

Hi, this is Kim Nazi.

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

Hi, Kim.

**Kim Nazi, PhD, FACHE – Veterans Health Administration – Management Analyst**

The purpose of – I just want to share with you some of the work that VA continues to do, because I think the goal is to also have government experience inform and we're happy to share any information that we can to support the Workgroup's efforts. So, I just would like to list a few of the projects as an update for the group and if you'd like more information in the future we would be happy to provide that.

Of course we have the VA Blue Button but I wanted to note that in January we significantly expanded the kind of information from the electronic health record that veterans can include in their Blue Button including progress notes, additional lab tests results, problem lists and all those different data types.

We also now offer the ability to view and download the VA C-CCD the continuity of care document currently it's a C32 stand but we are in the future moving to offering a C-CDA and then the next project associated with that in the spirit of VDT is really to not just view and download but enable transmit to Non-VA providers and systems using Direct protocol. So, we're actively working on that project and I know we've got some interfaces with ONC and others on that.

We also have VA Open notes partnering with the Robert Wood Johnson Foundation now that those visit notes are part of what a patient can access, view and download in their Blue Button record and then secure messaging and we've also done quite a bit of work in the patient generated data work space.

There are two recent articles in the *Journal of Medical Internet Research* that I just want to mention, because they do kind of summarize some of this work and the experience that we've had, the first is really focused on the PHR paradox and going back to Mary Jo's presentation really emphasizing the role that healthcare professionals play in being part of that reciprocal process to meet and engage patients and to endorse engagement.

And then the second article also in JMIR is from Dr. Woods and it really reflects patient's stories based on access to data including progress notes, so lots of opportunities to provide information and I'm so thankful to be a member of the group and thank you.

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

Thanks and Kim can you – if you can get the articles to Mary Jo we'll make sure that they're available to the team. I'd also like to suggest that we add the patient engagement framework from NeHC as some of our background documents and also we have some background work that some of you were on a team that I chaired on standards for Meaningful Use 2 we did a comment back about the standards to support patient engagement, if we can get that document as well and the if the team has been oriented to the FACA website, MacKenzie have we done that to let folks know where materials can also be found.

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

We had Altarum send an e-mail out that described the different functionalities.

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

Okay.

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

And I have sent the link out already.

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

Okay, so it's a really great resource for you because all of the information that we do in the Federal Advisory Committees are all public but it's great to have a place, a single place, for all of us to go and look at this background material so it's very, very helpful. Anyone else?

**Susan H. Woods, MD, MPH – Veterans Health Administration – Director of Patient Experience, Connected Health Office**

Hi, this is Sue Woods, thank you Kim, I work with Kim at the VA I'm the Director of Patient Experience in the Connected Health Office. Connected Health is trying to sort of reconcile our own patient facing applications that are now on the web point of care kiosk and our growing mobile Apps portfolio. The next sort of – the immediate thing that we need to focus on that we're focusing on right now like Kim said is patient generated data.

We're working on developing standards for data collection, data storage, management and then, you know, where the rubber really is going to hit the road on that which is the display of the data to the healthcare teams. We're going to be starting with some medications including patients being able to review and comment on their prescribed medications as well as entering other medications that they're taking on their own or from other providers.

The other thing I want to say not so much as a standards but I'm glad that the patient engagement discussion that we had previously also brought up the changes in thinking and behavior that needs to happen on the healthcare team side, it's pretty significant having access to things like notes for patients, it's a huge change in culture, it's a huge change in verbal and written conversations, secure messaging and now patient generated data is really going to change the workflow and we're really trying to work on how to sort of disseminate changes on the healthcare delivery side.

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

That's pretty exciting, thank you. Is there anyone else?

**Russell Leftwich, MD – Tennessee Office of eHealth Initiatives – Chief Medical Informatics Officer**

This is Russ Leftwich a couple of activities that are actually outside my pay job, but one is the effort that has taken off in the last month and I am leading to harmonize the care plan model of the S&I Framework longitudinal coordination of care initiative and HL7's patient care plan model that's being developed and will be balloted in September of this year, so this is in part an outreach to anyone who would be interested in being involved in that harmonization either through the S&I Framework, the longitudinal coordination of care or through HL7 the Patient Care Workgroup.

The second activity is one that I actually conceived on my own to get the pediatric community together and I convened a group of pediatricians in Nashville to develop through the HL7 process interoperability standards to address some of the gaps in pediatrics specific data that would enable patient engagement in the pediatric realm around a portable health records for the special needs children, EPFPT screening, growth chart and so we would also invite in both HL7, through HL7 in that activity.

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

That's great, Russ. Any other comments? Any others?

**Brian Ahier – Gorge Health Connect, Inc. – President**

Hi, this is Brian Ahier.

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

Great, Brian?

**Brian Ahier – Gorge Health Connect, Inc. – President**

Well, I just – last month I was having a little problem with the audio so I didn't get a chance to say hello to everybody and in the interest of time I won't go into too much detail. I've been involved with the Direct Project and Automate Blue Button and a wide array of standards and interoperability framework initiatives and just really happy to be here and I think that, you know, we'll have lots of opportunity over the coming months to work on some really interesting things.

I guess the one thing that I'm most excited about right now, you know, is having the patient in the middle of health information exchange and sort of the convergence now of patient and consumer engagement with health information exchange and really looking towards having patient mediated exchange and the patient involvement in their care. I think that "A" Attitudes is going to be possibly an area where we can find some technology solutions that might help us and help the ONC in that really important effort.

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

That's great, thank you Brian I'm glad you were able to have our audio situation resolved. Any other member?

**Yair Rajwan, DSc, MSc CS, MSc HIS, PFNLM – Visual Science Informatics, LLC – Director, Analytics Visualization**

Hey, Leslie, this is Dr. Rajwan from Visual Science Informatics.

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

Hi.

**Yair Rajwan, DSc, MSc CS, MSc HIS, PFNLM – Visual Science Informatics, LLC – Director, Analytics Visualization**

Hi, quick – it's amazing to see the progress that Erin has brought about the Blue Button+ we have been involved in Blue Button, the Blue Meter, from 2010 through Health2O so it's amazing to see how they're progressing very rapidly, but a quick question to you is what is our plans to do – I know we discussed and you mentioned in our last meeting that you are at least aware of several standards in content analytics and visual communication that are specific for consumer, health consumer and that's only one square in our spreadsheet that we need to fill, but are we planning to do some more brainstorm sessions that people will be able to contribute or should I reach to you one-on-one on those standards that you are aware of so we can include them in our table?

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

We will include them in our work plan but our prioritization of work will probably be informed by the immediate needs in Meaningful Use 2 followed by efforts that we think can support directional findings in Meaningful Use 3 and so I'd imagine it would come up in that area. So, we will be working on a priority scheduled based on the timeliness of need and right now we do have some urgent work as well. So, we will all work as a team to help prioritize that. I will be working with ONC and coming up with a straw man for our next meeting that we will be able to review, but please do keep that on the grid.

**Yair Rajwan, DSc, MSc CS, MSc HIS, PFNLM – Visual Science Informatics, LLC – Director, Analytics Visualization**

Excellent, thank you very much, appreciate that.

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

Any other team members? Okay, next slide. I'm going to have you go – each of you, there is a Word document that has been sent out we would like to update that document and send it to Mary Jo which we will compile. Next slide.

And so what we will do is take the inventory list of this team as well as a list of all of the standards that support Meaningful Use today and we'll look at gaps. We'll also look at where there will be opportunities for each of us to work on harmonization and leadership and/or information.

So, again, I think one of the key themes that we will be tasked with is harmonization and patient engagement is a green field, it's largely new and so we don't have the encumbrances of legacy standards in many ways we have an opportunity to make sure we've got harmony across all of the patient engagement standards and that helps us to advance patient engagement much faster.

Yesterday in the Standards Committee meeting a few of us were discussing the fact that I think this team is the no excuses team, it's the team that says, "Yes there is a standard for that and let me tell you how that could work," so very excited about the group. Next slide, please.

So, your homework is to complete the table of member activities that you're working on and send that to Mary Jo, and then as – please read and comment on the consumer strategy, this is as an individual, by May 9<sup>th</sup> on the planningroom.org and then the materials that we've talked about the articles and reference material your other piece of homework is to do that reading.

The next meeting we will – ONC team and I will compile these tables of inventory and skill sets and we'll look at where there are opportunities for harmonization input and leadership and start to make a priority work effort for the team. So, these first two meetings have been level setting in making sure we were all aware of each other's work and from here the work starts. So, I want to thank you all. Do we have any comments from ONC? I'm mindful of time; we're about two minutes over.

**Mary Jo Deering, PhD – Office of the National Coordinator – Senior Policy Advisor, Office of Policy & Planning**

No, just a reminder that also next meeting we will have the more technical deep dive into Blue Button.

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

Yes, that will be great. All right, any other comments from the team? Super, well, thank you and we'll try to be a little bit more on time next time. Thank you so much.

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

So, Leslie, I'll just open it up for public comment now?

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

That would be great.

## Public Comment

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

So, operator can you please open the lines for any 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're listening via your telephone you may press \*1 at this time to be entered into the queue.

### **Brian Ahier – Gorge Health Connect, Inc. – President**

Leslie, this is Brian Ahier while we're waiting for public comment will we always be having these meetings this early in the morning for those of us on the West Coast?

### **Leslie Kelly Hall – Healthwise – Senior Vice President, Policy**

We are looking forward to new scheduling, but we have scheduled out meetings I think through October and I don't think they're the same time each time.

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

The next meeting is actually scheduled for a Friday at 1 p.m.

### **Leslie Kelly Hall – Healthwise – Senior Vice President, Policy**

Yeah, thanks, Caitlin.

### **Susan H. Woods, MD, MPH – Veterans Health Administration – Director of Patient Experience, Connected Health Office**

This is Sue Woods; can I ask a question about the other...there is another consumer group?

### **Leslie Kelly Hall – Healthwise – Senior Vice President, Policy**

Yes.

### **Susan H. Woods, MD, MPH – Veterans Health Administration – Director of Patient Experience, Connected Health Office**

And is there any way for us to get some kind of a summary of their work? It seems to me that there would be important relevance and overlap.

### **Leslie Kelly Hall – Healthwise – Senior Vice President, Policy**

I sit on that as well so we will start adding to the agenda an overview of the previous meeting and then also point you to the direction of the minutes and/or the actual recordings, audio recordings and transcriptions of those meetings so that we can be kept informed. Thank you for that reminder.

### **Susan Hull, MSN, RN – WellSpring Consulting – Chief Executive Officer**

Good morning this is Susan Hull I had a little trouble with my audio earlier but I did post two questions in the comments section I can take them off line.

### **Leslie Kelly Hall – Healthwise – Senior Vice President, Policy**

Okay, thank you. Are there any public comments?

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

So, operator are there any public comments?

### **Rebecca Armendariz – Altarum Institute**

We have no comment at this time.

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

Thank you.

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

All right, thank you so much everyone. Have a good weekend.

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

Thanks everybody.

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

Bye.