HIT Standards Committee
Consumer Technology Workgroup
Transcript
March 21, 2013

Presentation

MacKenzie Robertson – Office of the National Coordinator
Thank you, good morning everybody, this is MacKenzie Robertson in the Office of the National Coordinator for Health IT. This is the kickoff meeting of the HIT Standards Committee's new 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 and transcribed so please make sure Workgroup members you identify yourself before speaking for that transcript. I'll now go through roll call. Leslie Kelly Hall?

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Leslie. Brian Ahier? Brian, are you on mute? I know you're on. Christine Bechtel?

Christine Bechtel, MA – National Partnership for Women & Families – Vice President
I'm here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Christine. Brian Carter was unable to make it today. AJ Chen?

AJ Chen, PhD – National Partnership for Action Region IX Health Equity Counsel
Yes, here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, AJ. John Derr?

John F. Derr, RPh – Golden Living, LLC
Here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, John. Tonya Dorsey?

Tonya Dorsey – Blue Cross & Blue Shield of South Carolina
Here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Tonya. Art Henderson? Susan Hull?

Susan Hull, MSN, RN – WellSpring Consulting – Chief Executive Officer
Here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Susan. Liz Johnson? Tom Jones?

Thomas Jones, MD – Tolven Health – Chief Medical Officer
Here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Tom. Mohit Kaushal? Sally Okun?

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

MacKenzie Robertson – Office of the National Coordinator
Thanks, Sally. Yair Rajwan?

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

MacKenzie Robertson – Office of the National Coordinator
Thanks, Yair. John Ritter?

John Ritter, MS – HL7 EHR Work Group
John's here, hi.

MacKenzie Robertson – Office of the National Coordinator
Great, thanks, John. Anshuman Sharma? Fred Trotter?

Fred Trotter – Not Only Dev – Founder
Here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Fred. Holly Miller?

Holly Miller, MD – MedAllies – Chief Medical Officer
Here.

MacKenzie Robertson – Office of the National Coordinator
Thank you, Holly. Russ Leftwich?

Russell Leftwich, MD – Tennessee Office of eHealth Initiatives – Chief Medical Information Officer
Here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Russ. Kim Nazi?

Kim Nazi, PhD, FACHE – Veterans Health Administration
Here, good morning.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Kim. Susan Woods? And were there any Workgroup members that were not on roll call that I missed? Okay, are there any ONC staff members on the line?

Brian Ahier – Gorge Health Connect, Inc. – President
I'm sorry, this is Brian Ahier and I chimed in earlier and then was muted, I'm here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Brian. Any ONC staff members who are on the line, if you could please identify yourselves?

Lauren Thompson, PhD – Office of the National Coordinator
Lauren Thompson is here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Lauren.

Farrah Darbouze, MPH – Office of the National Coordinator
Farrah Darbouze is here.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Farrah.

Mary Jo Deering, PhD – Office of the National Coordinator – Senior Policy Advisor
Mary Jo Deering.

MacKenzie Robertson – Office of the National Coordinator
Thanks, Mary Jo. Okay with that I'll turn the call back over to you, Leslie.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super, thank you very much MacKenzie. This is a really exciting time for all of us who promote patient engagement and hope to have a more coordinated and collaborative healthcare system. And we'll start with some opening remarks today from me and Christine Bechtel, and also Lygeia Ricciardi, if she has joined. I think that many of us have been passionate in contributing to patient engagement throughout our careers and being part of this Workgroup is very important for the work that we hope to do.

The Policy Committee has assigned a Consumer Empowerment Workgroup which Christine will talk about and this group is really tasked with defining the "what" and making recommendations for need and in policy. Our job is to look at "the how" what kinds of standards support empowerment? How can we support the policies and it's very, very exciting.

Some of the things we will be tasked with will be making sure there is parsimony in our efforts that any time we consider, review, recommend standards we're doing so in a way that really maximizes current efforts and makes use of standards that are highly used in the industry.

We have a great group of people and we'll go into introductions in a minute, but it represents skill sets from research, from consumer empowerment to technology informaticists, physicians, nurses, consumer advocates a wide range of people on this team and I'm very, very pleased and proud to be part of it and sharing this with Christine. So, I'll turn it over to Christine for her comments and then we'll go on. Christine?

Christine Bechtel, MA – National Partnership for Women & Families – Vice President
Sure, thanks, Leslie and welcome everybody it really is a momentous and terrific occasion that we're able to launch not one but two workgroups that are very focused on consumers and patients and their families would be another way to describe them, right?

So, thank you for being willing to serve I know there was just an enormous amount of people who were very interested in these two workgroups and we really need your expertise. So, you know, we often talk about the link between policy and standards, and I'm delighted that we have a really stellar group of folks on the policy side who want to dive in to issues that are now emerging because of the terrific progress in meaningful use and in health information technology, and in exchange that we have all been making for the past several years.

So, we're excited to be able to work with a group of experts who really know how to get it done and not just what exits out there that we can leverage but also is very dedicated to creating new approaches and I think, you know, many of you in your work previously clearly have done that and so I'm excited to be part of this group as well. Thanks, Leslie.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
You bet. Lygeia, have you joined?

MacKenzie Robertson – Office of the National Coordinator
No, she hasn't, we may want to just introduce Mary Jo and Farrah as well at this point.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
You bet. So, Mary Jo, would you talk a little bit about your role?

Mary Jo Deering, PhD – Office of the National Coordinator – Senior Policy Advisor
Thank you very much – Mary Jo Deering – I work in the ONC Office of Policy and Planning, where I am a lead on consumer eHealth policy activities and Lygeia, who is unable to be here, heads our consumer empowerment program activities. So, I'm delighted to be here I've been working in this space I'm going to tell you for multiple decades and am just delighted to see the launch of this workgroup.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you, very much Mary Jo. And Farrah?

Farrah Darbouze, MPH – Office of the National Coordinator
Hi, my name is Farrah Darbouze I'm working in the Office of Science and Technology which is Doug Fridsma's office in ONC. I am a program analyst and I mainly work on structure data capture initiative and also the modular specifications project. I'm really excited to help as much as I can with the Consumer Technology Workgroup.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you, very much Farrah. Let's go ahead and advance to slide number three, Caitlin, and we'll talk about – we'll go ahead and do introductions. As, I said, there is a wide group of people here and what I'd like to do is have you take a brief moment introduce yourself, the organization that you're with and represent, and maybe very briefly what you hope to bring to this committee. So, let's do this alphabetically and we'll start with Brian Ahier. Brian, are you on mute? Brian?

Brian Ahier – Gorge Health Connect, Inc. – President
Hi, this is Brian Ahier I'm the President of Gorge Health Connect and the Health IT Evangelist at Mid-Columbia Medical Center in Oregon. And just really looking forward to participating; we have a great group of folks here and I'm honored to be a part of it, thanks.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super. Christine, do you want to describe what you do?

Christine Bechtel, MA – National Partnership for Women & Families – Vice President
Oh, sure. So, Christine Bechtel at the National Partnership for Women and Families. We're a nonprofit, non-partisan consumer advocacy organization based in Washington, DC and also do a lot of work in communities trying to help healthcare providers partner with patients to improve the delivery system. So, we do lots of work on things like health IT quality measurement, public reporting, payment reform, things like that.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you, Christine and Brian Carter is not able to join with us. AJ?

AJ Chen, PhD – National Partnership for Action Region IX Health Equity Counsel
Yes, I'm AJ Chen I'm based in the Silicon Valley. I'm serving on the HHS National Partnership for Action Health Equity Counsel and my focus there is to promote or advocating using consumer technology to cite health disparities.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
That's great, thank you for joining. John Derr?

John F. Derr, RPh – Golden Living, LLC
My name's John Derr I'm a Pharmacist and I represent long-term post-acute care. I was the CIO of Golden Living which has 63,000 patients under its care at any one point in time. I'm on the Standards Committee, I'm on NQF HITAC Committee, I'm on a couple of other workgroups, chair the Pharmacy Consultant Foundation and have formed a long-term post-acute care HIT collaborative which has all of the stakeholders that are in long-term post-acute care as a member of an informal group. And, Leslie and I have been working on this for a while and I'm excited because we can extend the spectrum of care past the episodic hospitals and into more of the home care and getting the patient engaged. Thanks.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Great; thank you, John. Tonya?

Tonya Dorsey – Blue Cross & Blue Shield of South Carolina
Hi, I'm Tonya Dorsey I'm with Blue Cross Blue Shield of South Carolina. I am a chief implementation architect here. I also serve on the Privacy and Security Workgroup. I'm looking forward to leveraging some of what we're doing here as a plan and contributing to this workgroup around consumer technology, that's it, thank you.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you, Tonya. And did we – I don't think I heard Arthur on the call? So, Susan Hull?

Susan Hull, MSN, RN – WellSpring Consulting – Chief Executive Officer
Good morning everyone, Susan Hull, I'm a registered nurse. I live in Northern California, CEO of WellSpring Consulting and also recently have taken on a new role as chief health informatics officer with DiverseNet. I bring many decades of experience as both a practicing nurse, a consultant researcher, hospital healthcare administrator. I also had a chance to build a community health information network back when we called them CHINs, one that bailed but I've been a long staunch advocate for consumer empowerment and really bringing providers and patients together in new ways. I also Co-Chair a Workgroup within the Alliance for Nursing Informatics on Consumer eHealth.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super, thank you and I know that Liz is not able to join today. Tom Jones?

Thomas Jones, MD – Tolven Health – Chief Medical Officer
Hi, I'm Tom Jones. I'm the CEO of Tolven Health, an organization that has developed open source software for use in personal health records among other things, but equally importantly using personal health records as the pivot point for health information exchange so we have a couple of interesting projects that are live doing that.

The thing that I hope to bring to the committee is a concern that standards for information that is used by and entered by patients adheres to the same rigor for specifications for data type, vocabulary, messaging, formats, etcetera, etcetera as we want to have throughout the federal space so the consumers really are part of the stakeholder care group.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super, thank you, Tom. Holly?

Holly Miller, MD – MedAllies – Chief Medical Officer
Hi, I'm an Internist and I'm also the Chief Medical Officer for MedAllies and the Medical Director for the Taconic IPA which is an over 5000 physician organization in the Hudson Valley. I've long been interested in patient engagement and to that end particularly as we think about healthcare transformation and bending the cost curve for healthcare we're not going to be able to do that without patient engagement and there's already a lot of evidence that patient engagement supports those goals.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super, thank you, very much. Sally?

Sally Okun, RN, MMHS – PatientsLikeMe – Vice President for Advocacy, Policy & Patient Safety
Hi, good morning everyone, my name is Sally Okun and I'm from PatientsLikeMe. I am the Vice President of Advocacy, Policy and Patient Safety and have, until fairly recently, overseen our health data integrity team, a group of clinicians, I am a registered nurse myself, and we would oversee the heath data that is submitted by patients on the site. The platform itself is research-based, it's a registry model for patients so that they can collect health data about their own experiences and then that's aggregated and made useful for them to see other people like themselves experiencing similar things. We also have a social network built into it.

So, what I hope to bring – I work a lot on trying to create a patient vocabulary from the patient voice that we've spent a lot of time building and coding, and trying to make interoperable at some point when our system hopefully will be able to communicate with other systems so that we really bring that longitudinal view from the patient's voice and perspective over time into the electronic records and other venues that might want to have that perspective.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super, thank you, Sally and I'm going to insert Russ Leftwich here because I think that he's not on the slide but a member of the team as well. Russ?

Russell Leftwich, MD – Tennessee Office of eHealth Initiatives – Chief Medical Information Officer
Hey, Russ Leftwich, I practiced medicine in Nashville for 22 years for the past three years I've been the CMIO for Tennessee's Office of eHealth Initiatives, which is the state designated entity for health information exchange. I served with Holly the past two years as one of the leads of the S&I Framework transitions of care and now serve as one of the leads of the longitudinal coordination of care initiative in S&I. I'm a big believer that we need to transition to true patient centered team-based care and to enable that with technology and standards and my concept is that it needs to work like an NFL team not like a pickup game on Saturday morning which it does presently.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
That's great, thanks, Russ. Yair, is that correct?

Yair Rajwan, DSc, MSc CS, MSc HIS, PFNLM – Visual Science Informatics, LLC – Director, Analytics Visualization
Yes, excellent, pleasure meeting you all. Our two-year fellowship in informatics research at Johns Hopkins University was supported by the National Library of Medicine at NIH, our focus was how to use visual communication to enhance the patient engagement and enable shared decision making. We work with the state of Maryland of reducing significantly patient infection and hospital associate infection, and health associate infections; we are working with them on reducing infant mortality using visual communication and visual informatics.

Our motto is to create better content for better engagement. We use visual analytics and information visualization as a business and technology services that we specialize in the preparation of complex data for public presentation and making basically the public visual communication unforgettable so we make sure that the complex medical information is understood by the public and engage them.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super, thank you. John Ritter?

John Ritter, MS – HL7 EHR Work Group
Hi, this is John. I'm a software engineer, I'm also a volunteer with HL7, I'm one of the co-authors of the EHR System Function Model. I'm an EHR Workgroup Co-Chair there and I'm also one of the authors of the PHR – that's the Personal Health Record System Function Model, I'm a co-facilitator there.

And I'm one of the co-founders of the International Mentoring Committee. The goal there is to take the standards we develop and find a way to get them all around the world and there is also a new Mobile Health Workgroup in HL7 that is finding ways to use the new handheld devices in intelligent ways and the mHealth aspect and I'm one of the mentors there. And I'm on the low and medium income country, that's the LMIC, subgroup, trying to find specific ways to get healthcare into the hands of those community-based workers in LMIC settings.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super, thank you. And Anshuman was not here is that correct?

Anshuman Sharma, MS – Ubiqi Health, Inc. – Co-Founder and Lead, Product Development & Technology Strategy
Actually, I joined late so I am here, thank you.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you.

Anshuman Sharma, MS – Ubiqi Health, Inc. – Co-Founder and Lead, Product Development & Technology Strategy
All right, I'm Anshuman Sharma I'm a co-founder of Ubiqi Health, and we're especially excited about the charter of this group as it pertains to consumer centric data or rather secondary data and the means of sort of elevating the status of secondary data to be able to directly use in the care continuum rather than just for patient engagement as it's been done so far from a fitness, wellness perspective. So, at Ubiqi Health we're looking at pain related therapies and how we can use a patient reported or secondary data and allow it to increase information content and the way it's captured such that it can be readily used in the process of delivering care and participating in making processes as well.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super, thank you. Fred?

Fred Trotter – Not Only Dev – Founder
Hi, my name is Fred Trotter and I've worked on open source healthcare software and written some books on health IT. My current title is healthcare data journalist, and people keep asking me what that is and I promise once I figure it out I'll tell everybody.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Great, thank you. Kim?

Kim Nazi, PhD, FACHE – Veterans Health Administration
Hi, good morning everyone I'm Kim Nazi with the Veterans Health Administration. I've been with VA for 30 years and last fall I just completed my PhD in sociology so I've got a foot in kind of the practical operations arena but also the research arena. Most recently, for the last few years, I've been very much focused on the VA Blue Button effort and I can think of several projects that the discussions from this workgroup and recommendations will help to inform and I also hope to be able to bring some of the VA experience to contribute to the group. So, thank you.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you. Susan Woods?

Susan H. Woods, MD, MPH – Veterans Health Administration – Consumer Health Informatics Specialist
Hi, this is Sue Woods I'm also with the Veterans Health Administration I'm a primary care physician out also in Oregon and a consumer health informaticist. I work actually a lot with Kim on Web and mobile app development. I am passionate about participatory care and look forward to working with this group.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you. Did I miss any team members that are on the phone? So, I'll introduce myself, I'm Leslie Kelly Hall. I'm the Senior Vice President of Policy for Healthwise which is a nonprofit health education company and patient engagement organization for about 36 years now. I'm a former chief information officer and vice president of marketing of the health system here in Idaho, the founder of the Idaho health data exchange and sit on the Health Information Technology Standards Committee as well as the Meaningful Use subcommittee, Privacy and Security of the Standards Committee, and others.

And I am very, very pleased to be part of this group because all of us have been making an impact in this area and it's wonderful to bring that all together and to be able to demonstrate and to show the great work that's going on. So, next slide, please?

So, our charge is to provide recommendations on standards and interoperability issues and opportunities related to strengthening the ability of consumers, patients and lay caregivers to manage health and healthcare for themselves or others. So, we are really about taking the policy that's coming out of Christine's group recommendations and making sure that there are great standards and no excuses in data to make sure that patients are engaged.

So, some of our scope or examples of issues to be addressed include portability, patient access and generation of their own health data and incorporating patient preferences and values for a variety of issues such as care plans. So, we will be having other workgroups that we interact with one is, as I mentioned, the Consumer Empowerment Workgroup that Christine chairs, that is really an important group that we will be working with and providing support to both in recommending standards that policy recommendations come from and also identifying standards that can help promote policy vision that comes out of that group. And also, we support the Meaningful Use Workgroup as well. Next?

So, MacKenzie, were you going to talk a little bit about this process for procedures for the workgroup?

MacKenzie Robertson – Office of the National Coordinator
Yes, so, thank you Leslie. My name is MacKenzie Robertson I'm the FACA Program Lead within the Office of the National Coordinator, and FACA stands for the Federal Advisory Committee Act. It's also just a term that we use to refer to both advisory committees that we have within ONC. My job is to manage both the HIT Policy Committee and the HIT Standards Committee and all of its workgroups, this one included.

I just wanted to give everyone a little bit of background on the advisory committees and how they function since this maybe the first time you've been involved with the committees or the workgroups. So, the HIT Standards Committee is a Federal Advisory Committee subject to the Federal Advisory Committee Act also known as FACA. The FACA was enacted to insure that advice by various advisory committees formed over the years is both objective and it's accessible to the public. The act also formalized a process for establishing, operating and overseeing the advisory committees.

The HIT Standards Committee specifically, which is the parent committee to the Workgroup is charged with making recommendations to the National Coordinator for Health Information Technology on standards, implementation specifications and certification criteria for the electronic exchange in use of health information and the committee is advisory in nature it provides recommendations, and the recommendations that it provides is just advice, ONC takes it to heart but it is not by any means binding for ONC.

So, the committee is allowed to form workgroups to focus on specific tasks or charges. The Workgroups themselves cannot provide recommendations directly to ONC the process is that the Workgroups would develop recommendations to present back to the HIT Standards Committee and the HIT Standards Committee would deliberate on those recommendations and then provide their own set to ONC formally through a transmittal letter. So, the workgroup reports directly to the Standards Committee.

ONC values the public partnership that the committee provides and they made it policy at the very beginning of the committee that all Workgroup meetings would be held in the public forum and they welcome public input at the end of each meeting. So, as you'll see today we do have public comment built into the workgroup agenda at the end.

The public comment period we limit to three minutes and it is just that it's an opportunity for the public to provide comment and the workgroup members are not required to respond directly back or answer any of the questions that are proposed.

So, the majority of the workgroup calls are held virtually, it allows the committee members to discuss any topics or charges that they've been charged with. Other tools that are available to the workgroup to gather additional input from outside experts are listening sessions.

So, the workgroup members can invite outside experts to present to the workgroup during their virtual calls, if more information is needed we can hold – the workgroup can hold hearings, the hearings are usually day long with multiple panels and several panelists per panel and that gives an opportunity for the experts to provide testimony to the workgroup to help in their deliberations in preparing recommendations to present back to the Standards Committee.

We also have a health IT buzz blog on the ONC website, so the workgroup is able to post any notifications that they would like regarding workgroup activities or if they want to put out a call for public comment they can use the blog to do so.

And then just lastly, the administrative details, each workgroup meeting we do, as I mentioned in the beginning have a transcript and recording kept and they are posted on the ONC website within a few days of each workgroup meeting so that's always a great resource for Workgroup members and members of the public to see what's happening on all the workgroup calls.

And process-wise any calendar appointments or meeting materials that are distributed regarding the Workgroup will come from the ONC FACA meetings email account, having it come from one e-mail account I think is just easier for everyone to be able to search for emails and see the materials that they'll need for the call. So, with that I'll just say, thank you again for agreeing to participate in the workgroup and open it up to any questions that you might have.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
MacKenzie do you want to talk about some of the resources like the FACA member website where we can look at previous materials or the library of resources that we have?

MacKenzie Robertson – Office of the National Coordinator
Sure, so another aspect of the workgroup membership is we do have a FACA portal and workgroup members have access to that. We can post resources for the Workgroup members to be able to access so we are not necessarily inundating your email inboxes if the documents are very long and they also post membership lists and the meeting minutes and transcripts on the FACA portal as well. So, I will send an e-mail out to all the Workgroup members for both this Technology Workgroup and the Consumer Empowerment Workgroup letting them know how to access the portal.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
And it's very useful because you can see related testimony that has been done in other committees so I encourage you to get familiar with the portal. Great, next slide. So, MacKenzie do you want to talk about this too?

MacKenzie Robertson – Office of the National Coordinator
Yeah, sorry, yes I forgot there were two additional slides. So, I also included in the presentation two org charts, the first one being the HIT Standards Committee which references all the Workgroups that are currently active. So, the HIT Standards Committee is chaired by Jonathan Perlin and vice-chaired by John Halamka. And we have our new Consumer Technology Workgroup which is listed on the top.

The other active workgroups currently on the committee are the Clinical Operations Workgroup, the Clinical Quality Workgroup, the Implementation Workgroup, the Nationwide Health Information Network Power Team and the Privacy and Security Workgroup.

And you'll find some of the members on this group are also members on some of the other Workgroups that I just mentioned. So, this is the organizational chart for the HIT Standards Committee and the next slide is the HIT Policy Committee and all the workgroups that have been formed underneath the Policy Committee. Dr. Farzad Mostashari is the chair of the Policy Committee and is vice-chaired by Dr. Paul Tang, and as you can see the Consumer Empowerment Workgroup is listed up on top that is chaired by Christine Bechtel.

We also have the Certification Adoption Workgroup, the Governance Workgroup, the Information Exchange Workgroup, Meaningful Use Workgroup, Privacy and Security Tiger Team and the Quality Measures Workgroup. And if you are interested in finding out what the other workgroups are charged we do have on the ONC website a landing page for each of the different workgroups and we've also added one for this new Consumer Technology Workgroup.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
And it's important to note that although the charge of these committees often revolve around meaningful use, our scope is really looking at or could look at a broader impact of recommendations and standards as we align with other work teams or are providing opportunities to support policy coming from those other work teams. So, we might see some cross pollination of work and so I'm not sure if either Christine or MacKenzie would like to talk a little bit about that.

Christine Bechtel, MA – National Partnership for Women & Families – Vice President
Well, Leslie, do you – I think the next slides are some of the, you know, Stage 2 Meaningful Use stuff.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Okay.

Christine Bechtel, MA – National Partnership for Women & Families – Vice President
Do you want me to go into that which would provide some guardrails?

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
That would be wonderful thank you.

Christine Bechtel, MA – National Partnership for Women & Families – Vice President
Okay, so on the next slide you will see that what we thought we'd do is do a quick overview for you guys. Most people will know this, but these were some of the main things that we will see in the second phase of meaningful use. So, it gives you a sense of kind of where the touch points are with the Meaningful Use Workgroup as well.

So, the first is what we call view, download and transmit or VDT this is the Blue Button type of functionality where a patient or family who is authorized can go on-line and download their own health information there are lots of work being done in the standards world right now that you guys are probably familiar with around Blue Button, but this applies to both eligible providers as well as to hospitals and so patients can get this within 36 hours of discharge for example.

So, on the next slide you'll see that the objective is the clinical summary for patients so this is what we call the after visit summary or the office visit summary and so it's got, you know, kind of a standardized set of data that would go on this summary and the intent here was for patients to continue to know, you know, what just happened, what happens next, what should I expect etcetera and this was something that was in the first stage of meaningful use and it's just been continued into the second phase.

On the next slide you will see, I think its secure messaging, yeah, oh, patient specific education resources. So, again, this is a continuation of some of the work that began in the first stage of meaningful use but this is the idea that I think it's using the HL7 InfoButton, the EHR can go out and in a more automated fashion and hopefully easier fashion, identify patient specific educational resources that really fit with some of the, you know, diseases or conditions, or disease states that a patient maybe incurring at the time. So, that will continue here as well and that's more than 10 percent of all patients would actually get resources for both the hospital and the providers or the professional side.

So, next slide is secure messaging, this is new to Stage 2, so there will be a secure message sent by patients to providers and the ask here is this is physician practice only and it's about more than 5 percent of unique patients would actually send a secure message at some time in the, you know, year-long reporting period.

So, as you can see this sets some important context for the work that this group will do because it tells you a little bit about the tools that you have at your disposal and, you know, kind of what's happening in the broader environment, trends to leverage in terms of where consumers and their family members will be, you know, beginning later this year and really in earnest in 2014. So, that's exciting.

But, it also tells you that there are probably some real issues that at least from my view on the policy side are going to come into play that ONC needs help thinking through for consumers and then we need the sort of set of standards that might, you know, enable any kind of new functionality. So, one of those potential areas that I think that's going to be an interesting one is in the area of care planning.

And on the next slide you'll see that care plans were – there's some fundamental building blocks for care plans in Stage 2 of meaningful use, which is that as part of the care summary and that's the provider to provider summary, which is different from the visit summary I just described.

So, the provider to provider summary begins in Stage 2 to include some things like patient goals and instructions and lists of care team members and then in Stage 3 there's a proposal – well, it's in the RFC anyway, there's a proposal for a much more potentially robust care plan and you can see on the screen here what that might look like and it's really proposed for future stages, but there are discussions about bringing it forward into Stage 3.

But this is the idea that, you know, a care plan begins to really be driven by patient goals but that it would also include medical diagnosis in stages, functional status including activities of daily living, social and financial information, environmental factors that might affect the patient's health, you know, what patients can expect in terms of their course of illness or conditions, also more of a comprehensive cross setting team member list and how you would actually contact them. I could imagine this including their like Direct address too.

We talked a little bit about long-term goals for care, any kind of an advanced care plan or an advanced directive and the care setting where that would be executed for example. So, it's a much more robust concept and there's lots of discussion about moving that forward because it is so integral to certainly patient and family engagement but also care coordination, you know, if you think about the broader environment of payment right now accountable care organizations, etcetera, care planning is something that could really facilitate better performance under those models and so I think that raises a lot of issues and it's one thing that the Consumer Empowerment Workgroup of the Policy Committee is going to start to take on, so, we just wanted to flag that. And then I think now I can turn it back to Leslie.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Great and I think part of our work will be making sure that the standards we recommend or that we participate in creating supports this future vision and this is what I meant earlier by the scope outside of the immediate needs of meaningful use, this is really a vision that's come forward from the Policy Committee, it's been discussed like a platform, it's been discussed as a communication structure or as a collaborative care platform using standards to create this new coordinated care model.

So, we're very excited to see this working hand and glove with policy so as things are described we make sure that the standards are supporting the kind of flexibility and kind of vision in the future that's been described to us. Next slide, please?

So, our initial tasks are really to identify standards for the portability of patient data and standards for Meaningful Use Stage 3 patient and family engagement objectives not assigned to other Standards Committee Workgroups which are really around the consumer and the patient engagement. Next slide.

So, we will be identifying issues related to patient data portability. At the next workgroup meeting we will dive into data portability and we will be briefing, getting a briefing from ONC on projects that may raise issues for the workgroup to address and to identify, and prioritize other topics that the Workgroup should address in the future, so we'll still be doing some orientation, some learning and assigning our work tasks. Next slide.

So, before we take public comment I did want to ask the group briefly to describe the specific standards you are working on, you are advancing or promoting or currently interact with today that support patient engagement so that we just get an idea as a group the tremendous inventory of skills that we have here in this group and I'd like to perhaps, Caitlin, let's go back to the alphabet slide and we'll just go in that same order. So, I think we start with Brian Ahier. Brian? Brian are you still with us?

MacKenzie Robertson – Office of the National Coordinator
I think it takes them a minute to get off mute, maybe we should go to the next person and then come back?

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Okay, so, all right, AJ Chen?

AJ Chen, PhD – National Partnership for Action Region IX Health Equity Counsel
Yes, what was the question again?

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
I would like to know what standards you are currently either working with, advancing or promoting that support patient engagement. So, we're just going to get an inventory of the current work efforts each of us are doing.

AJ Chen, PhD – National Partnership for Action Region IX Health Equity Counsel
Okay, I'm working specifically on the applications and data capture for screening that supports the ACA preventive care which is directed towards or designed for consumers. So, we're still figuring out what needs to be actually captured and also how to support the application and hopefully that will, you know, relate, you know, the experience hopefully will relate back to the standards that we are talking about.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Great. John Derr, are you still with us? I do know that John is actively working on the long-term post-acute care and transitions of care work and involved heavily in those S&I Frameworks. Tonya? Brian Ahier, are you with us, off mute? Hello?

MacKenzie Robertson – Office of the National Coordinator
They're both still on the line.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Okay.

MacKenzie Robertson – Office of the National Coordinator
I don't know if – Tonya, are you there?

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Okay, Susan Hull?

Susan Hull, MSN, RN – WellSpring Consulting – Chief Executive Officer
Thank you, I think, the thing that I'm working on that could be helpful is harmonizing standards for patient generated health data and, excuse me I think I was on the speaker, I just turned myself off. So, in terms of harmonizing standards for patient generated health data we've been following the model that Paul Estabrooks, Maureen Boyle, Russell Glasgow and others have developed as part of the More Project and created actually a patient profile that builds in patient preferences, lifestyle, social determinants of health plus patient reported data on healthy behaviors as a core. If you're familiar with that work they have identified about 14 items that they're recommending be part of the standardization of that from which we can really drive more preference sensitive care and, you know, customize care.

I'm also working on a shared care plan that builds in both the requirements that you've, you know, kind of previewed for Stage 3 but begins to look at actually outcomes of the care plan that are transparent with feedback to the patient and to the provider and distinguishing between adherence to the care plan and outcomes of the care plan, so both of those feedback loops facilitated by both mobile devices, sensors, other sorts of data input as well as patient generated data on outcomes and adherence.

And then I'm also working on an interesting project that's bringing together a mobile health wallet and so we're struggling with some of the initial standards and needs for consumer mediated health exchange to be able to not only download their Blue Button health data from many sources including health information exchange but then how to share and exchange and update that data over time as part of a mobile personal health record.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super, thank you. Tom?

Thomas Jones, MD – Tolven Health – Chief Medical Officer
Yes, relevant activities – I'm currently chairing the HIMSS HIE Committee and within that committee there's a subgroup that is busily working on a white paper for consumer engagement in how HIEs should be fostering it. I'm also chairing the HIMSS Healthcare Information Standards Workgroup and we have just begun our work but as part of our charter we are going to be looking at how overlapping standards actually damage interoperability and coning down on how we can prevent redundancy and proliferation of standards so that we don't end up with that awful joke about everybody loves standards that's why we have so many of them.

I'm on the executive committee for the Clinical Information Modeling Initiative which is an international organization that is dedicated to creating open source information models for interoperability across the world and I'm also a member of the Architecture Counsel for Open Health Tools. So, in all of those activities my interest is not so much in creating new standards as in leveraging and rationalizing the standards we have.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Super. Holly, are you able to join us and provide comment? Okay, Sally?

Sally Okun, RN, MMHS – PatientsLikeMe – Vice President for Advocacy, Policy & Patient Safety
Hi, well at PatientsLikeMe we are working on a number of different mechanisms to improve our ability to create persona-based user design and user experiences so that the health data we're collecting is certainly engaging the patients enough where they're interested in wanting to share the data in a way that they can then have it be usable for themselves as well as in their clinical encounters. So, we have a couple of ways that we're working on that. One is that we are creating an open science patient reported outcome development model and that platform has just recently been funded through a project with Robert Wood Johnson Foundation.

We'll be working with researchers, clinicians as well patients to begin to iterate on patient reported outcomes that matter to patients and then start to deploy, iterate again, deploy and then ultimately try to validate those using standards along the way as we do that development process.

More specifically for patients in building their profiles we are looking for their patient experience to be a structured and quantifiable experience but yet still delightful enough for them to want to do the entry and we're looking for information on their experiences with symptoms, side-effects and treatments, and all of those get coded against the standardized terminologies that are typically used in EHR formats and so then taking that information and ultimately coding that against a patient vocabulary so that we begin to start creating an environment where the information that's used by patients in their own voice could ultimately be understood in the clinical perspective as well.

So, I think, what – the last thing I would say is that we are also trying to create in some ways this care planning model where the patient is actually developing their care plan pre-visit so that they can have that available to them at the point of care, but we're trying to tailor that to the need of the clinician that they're going to see.

So, we have a demonstration project right now with the VA where we're creating a provider portal for their patients who are coming in with epilepsy. A neurologist helps us build the care plan so that we can actually have the patients bring in or the provider can access before the visit the patient reported data and structured surveys about their seizure activity and the kinds of things that the patient's attribute the triggering of the seizure to. So, again, trying to work with the patient reported information and build that into something that's already existing so we're not re-creating anything but we're actually trying to fit within the structured models that currently exist.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you, Sally. Russ?

Russell Leftwich, MD – Tennessee Office of eHealth Initiatives – Chief Medical Information Officer
Yes, two things and I'll be brief, but I'd welcome anybody's engagement off line. I was recently asked to lead the harmonization effort between the longitudinal coordination of care initiative and S&I Framework and their care plan model that's been developed over the past 18 months and the patient care group in HL7 that has developed over the past 2 years a care plan model that will be balloted for the first time in the current ballot cycle of HL7 and to try to harmonize those two efforts to the betterment of both.

And, I will call out my favorite standards gap as part of this which I think is the need for a care team roster standard that has a robust data set that includes a unique identifier for the members of the care team and their role with respect to this particular patient and when the patient was last seen, otherwise I think care coordination can't be coordinated.

My other role is I've been appointed chair of the HL7's Health Professional Engagement effort with the intent of involving more health professionals across the whole spectrum who are currently active in seeing patients and understand the workflows and data needs of their particular domains.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Great, thank you Russ. Yair?

Yair Rajwan, DSc, MSc CS, MSc HIS, PFNLM – Visual Science Informatics, LLC – Director, Analytics Visualization
Hi, we don't work on official standards we actually are trying to create de facto standards in two areas so we are working now with primary care physicians, nurses dealing with the obesity in New Jersey, diabetes and congestive heart failure. We are actually working with marketing companies that work on content for patients on primary care physician websites. There are two standards that we're trying to work with them. One is on content analytics and the other one is visual communication.

On the content analytics we're trying to promote more scientific approach standards to their content, so what they do currently is they're doing trial and error, they put content, they see how many people are actually reading it and they're doing it after the fact. What we're trying to promote is standard-like readability tests and grade level, like the smoke, so we know that they are evidence-based, that the simple measurement is very efficient in measuring great levels and readability and it's not effectively spread in the industry.

So, we are basically trying to spread that content analytics using measurement and metrics that will help them not only to identify are they creating content at the grade levels that they need to do, but where are the issues in their content and how to improve it so it will be readable in a diverse demographics especially in a decreased literacy, health literacy.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you.

Yair Rajwan, DSc, MSc CS, MSc HIS, PFNLM – Visual Science Informatics, LLC – Director, Analytics Visualization
The second standard we are trying to promote with people – again providers and practitioners at the state level like Maryland State Healthcare is the visual communication for consumers, so how do you take complex data, healthcare data to consumers and patients in a multi-culture and diverse demographic and present it in a visual way using information visualization. So, those are one of the two de facto standards we are trying to build from the ground up and spread it in the industry so they can use it for better content, better engagement.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
And I would be happy to talk with you offline about some of the standards that already exist in that area as well. John Ritter?

John Ritter, MS – HL7 EHR Work Group
Hi, guys, as I said before I'm working on the EHR System Functional Model which contains conformance criteria that are being used right now in the United States to help certify EHR systems, it's twin, it's sibling is the PHR System Functional Model by which personal health record systems might be able to be certified in the future as well.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Great, thanks.

John Ritter, MS – HL7 EHR Work Group
Also, I'm working on a usability section for each of those.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Oh, okay.

John Ritter, MS – HL7 EHR Work Group
So each of those types of systems can have metrics by which not only are the systems able to be used but to be able to measure the usability of those systems.

Also, on the public health side of things I'm working on eight domains of public health that are going out for ballot on Monday for vital records, early hearing detection, chronic disease cancer surveillance, public health lab, occupational disease and injury health statistics, deep vein thrombosis, birth defects and adverse events. So, those are all the items that the doctors should be able to collect on the public health side of it some of which the consumer may be interested in getting.

And I mentioned before also on the mobile health side of things I'm working with a new Mobile Health Workgroup to try to find ways to get some of this data into handheld devices and to be able to empower their consumers to use that and share some of that information back with the providers.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you, John. And Anshuman? Okay, Fred?

Fred Trotter – Not Only Dev – Founder
Hi, I'd just like to say that as the last member I'm totally supportive of this notion that we go alphabetically so I get to think about what I'm going to say the whole time, I really love it.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
It's reverse order next week or next month.

Fred Trotter – Not Only Dev – Founder
Oh, no, is it really, because, you know, I was going to say to Brian that, you know, he's been getting the lunch first and all this from his grade school and now karma, you know, karma is frustrating.

Okay, so, it's interesting because it sounds like a lot of what other people were saying is actually the exact the opposite of what I've been doing. What I – the question that I think about is what do patients want to actually do today and are trying to do with technology that they're not able to do?

So, you know, obviously my experiences of…I was one of the Founders and designers of the Direct Project, it's the one that I feel the least guilty about not working enough with, but I'm familiar with the run super API which is a popular quantified self-application, other quantified self-stuff like Fitbit, I work with a lot.

I know about the HealthVault API, Toland, you know, has a…has an API the smart API which is of course and extension of the old, you know, API. Robert Wood Johnson had an API that was something that could be used to develop Apps directly for patients, Allscripts … have APIs and of course now there's Blue Button and Blue Button Plus.

So, as I look at all of these things and I look at either tools that are developed with these standards or the patient being able, in the case of the Direct Project and Blue Button, to kind of get really low level benefit access to this stuff I'm very, very concerned about the degree to which these are de facto standards, so you can think about like Microsoft Word was a de facto standard, it's become more open over the years but it's been a de facto standard for documents and these de facto standards have problems including licensing and they fact they're not truly open.

There are issues like device crippling, so for instance you have to pay to get real low level access to your Fitbit for instance and of course I'm very concerned about Hugo and his defibrillator, and I'm interested in patient access.

I'm also interested, and I think this is probably one of the most significant things that I care about is actually real world use and real world bulkinzation of these various standards that are intended to give patients direct benefit but instead mean that they're, you know, using 15 different platforms and they can't get stuff to talk, I mean, it's kind of just a fundamental problem.

So, I have a much more practical and applied bend it sounds like than a lot of the other people, so hopefully that will be complementary.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Hopefully, I believe this all will be complementary and I'm very excited to hear about the work that's being done in this team and maybe reaching out to each of you where documentation exists on the work that you're doing so that we can start developing a library and knowledge about the work that we're doing, because I think it's both the differences and the similarities bring us a great strength as a team. I'm mindful of time and I believe, MacKenzie we need to open for public comment?

MacKenzie Robertson – Office of the National Coordinator
Yes we do. Operator, do you want to open the lines for public comment please?

Kim Nazi, PhD, FACHE – Veterans Health Administration
And also, this is Kim.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Okay.

Kim Nazi, PhD, FACHE – Veterans Health Administration
I do have a number of projects that I'd like to put on the table because I think they're very relevant, but I'm happy to do that at the top of the next call.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
That would be wonderful, thank you, Kim; I did not mean to cut us off except to be mindful of time. So, we will continue where we've left off at the top of the call next time.

Kim Nazi, PhD, FACHE – Veterans Health Administration
Okay.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you.

Public Comment

MacKenzie Robertson – Office of the National Coordinator
Operator, can you please open the lines?

Caitlin Collins – Project Coordinator – Altarum Institute
If you are on the phone and would like to make a public comment please press *1 at this time. If you are listening via your computer speakers you may dial 1-877-705-2976 and press *1 to be placed in the comment queue. We do not have any comment at this time.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
Thank you. So, look for a poll that will be coming about times for the next meeting and also more information as we schedule our events in the future. MacKenzie or Farrah did you have anything to add?

Farrah Darbouze, MPH – Office of the National Coordinator
I just wanted to say thank you to all of the…this is Farrah, I just wanted to say thank you to all of the new Workgroup members and I look forward to working with you as we progress with our work this year.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
All right, super, Christine any closing comments?

Christine Bechtel, MA – National Partnership for Women & Families – Vice President
No, I'm looking forward to work and collaboration, thank you.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy
All right, me too. Thank you all very much and I look forward to the next meeting.

MacKenzie Robertson – Office of the National Coordinator
Thank you everybody.

W
Thank you.

M
Bye-bye.