

**HIT Policy Committee
Consumer Empowerment Workgroup
Transcript
March 19, 2013**

Presentation

MacKenzie Robertson – Office of the National Coordinator

Thank you. Good afternoon everybody; this is MacKenzie Robertson in the Office of the National Coordinator for Health Information Technology. This is the first meeting of the HIT Policy Committee's new Consumer Empowerment Workgroup. This is a public call and there is time for public comment built into the agenda. The call is also being recorded and transcribed, so workgroup members please make sure you identify yourself before speaking. I'll now go through the roll call. Christine Bechtel?

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

I'm here.

MacKenzie Robertson – Office of the National Coordinator

Thanks Christine. Korey Capozza?

Korey Capozza – HealthInsight – Consumer Engagement Director

I'm here.

MacKenzie Robertson – Office of the National Coordinator

Thanks Korey. James Cartreine? Scott Fannin? Leslie Kelly Hall?

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks Leslie. Katherine Kim?

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

Hello.

MacKenzie Robertson – Office of the National Coordinator

Thanks Katherine. Sarah Krug?

Sarah Krug – Society for Participatory Medicine – President

I'm here.

MacKenzie Robertson – Office of the National Coordinator

Thanks Sarah. Rita Kukafka? Patricia MacTaggart?

Patricia MacTaggart, MBA, MMA – George Washington University

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks Patricia. Beth Morrow? Jan Oldenburg? Casey Quinlan? Clarke Ross?

Clarke Ross, DPA – American Association on Health and Disabilities

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks Clarke. Mark Savage?

Mark Savage, JD – Consumers Union – Senior Attorney

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks Mark. MaryAnne Sterling?

MaryAnne Sterling – Sterling Health IT Consulting, LLC – CEO

I'm here.

MacKenzie Robertson – Office of the National Coordinator

Thanks MaryAnne. Ann Waldo? Ryan Witt?

Ryan Witt – H4Y Corp

I'm here.

MacKenzie Robertson – Office of the National Coordinator

Thanks Ryan. Terry Adirim?

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

I'm on the phone.

MacKenzie Robertson – Office of the National Coordinator

Great, thanks Terry. Cynthia Bauer? Bradford Hesse? Kim Nazi?

Kim Nazi, PhD – Veterans Health Administration

Here.

MacKenzie Robertson – Office of the National Coordinator

Thank you Kim.

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

Somebody's on a cell phone, MacKenzie so you're cutting out. So if everybody could mute their phone that would be great.

MacKenzie Robertson – Office of the National Coordinator

Okay. Danielle Tarino?

Danielle Tarino – Substance Abuse and Mental Health Services Administration

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks Danielle. And Teresa Zayas Caban?

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

Here.

MacKenzie Robertson – Office of the National Coordinator

And did I pronounce that correctly?

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

Close enough.

MacKenzie Robertson – Office of the National Coordinator

Okay. Thanks. All right everybody, with that I will turn the agenda back over to Christine Bechtel, the Chair.

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

Great. Well welcome everybody; it's a momentous occasion here at our very first meeting. I have to say that I was told by ONC that the response to the public call for membership of this workgroup was really overwhelming. So, I think that's an exciting indication of where we are today and how far we've come in health information technology, that it's not just about the healthcare provider community anymore, but really about consumers as well. So, welcome. We've got quite an agenda today for you. We're going to start with doing some introductions so we can all get to know each other a little bit, beyond the name roll call that MacKenzie just did, of course. And that's going to include some introduction from Leslie Kelly Hall, who is chairing a companion workgroup to ours under the Standards Committee that will focus on consumer technology that we will work very closely with. So we'll ask Leslie to introduce herself in a moment.

But we're really going to go through kind of what's the scope of this thing and how do we fit with the other workgroups of the Health IT Policy Committee. We've asked MacKenzie to talk a little bit about the processes and procedures for FACA Workgroups and the different tools that we have at our disposal, because I think a lot of you are new to a workgroup of this nature. Some of you are old hands, but many of you are new. And then we're going to talk a little bit about Meaningful Use Stage 1 and 2 in terms of what was in there for patient and family engagement, to spur your recollection and talk a little bit about how the environment is changing. But we're really going to dive right in to talking about our initial task and kind of getting a work plan together. So, that's the purpose of today's call. So we're going to do some introductions and I'm going to ask Leslie and Lygeia Ricciardi to introduce themselves first, and then we'd like to have the workgroup members introduce themselves. We have a lot of you, because the call was so responded to. So, I'll just ask that we are careful about how much we spend introducing ourselves, but we'll go around and have folks talk a little bit about their organization and experience would be terrific.

So starting out, I'm Christine Bechtel and I work with the National Partnership for Women and Families, which is a non-profit consumer organization based in Washington and I do also serve on the full Policy Committee as well. Leslie, do you want to go ahead and introduce yourself?

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

Sure. I'm Leslie Kelly Hall and I'm the Senior Vice President of Policy with Healthwise, and we are a non-profit of about 35 years, helping people make better health decisions. I'm a former Chief Information Officer. I currently serve on the Standards Committee as well as the Meaningful Use sub-committee's Privacy & Security Committee and am a board member of NeHC and also DirectTrust.org. So I spend a good deal of time trying to connect dots for consumers. So the great policy work is backed up by good standards and no excuses. So, look forward to the outcome of these committees. Thank you.

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

We're going to hold you to that Leslie, good standards and no excuses. I like it.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

You bet.

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

So, Lygeia, our illustrious ONC Director of the Office of Consumer eHealth.

Lygeia Ricciardi – Office of the National Coordinator

Thanks Christine. Just wanted to say a quick hello, thank you and welcome. This is a really exciting moment because we've been talking about having a consumer-focused workgroup for more than a year, and finally it's a reality. And we're so excited that we have both one that focused on policy and one that focused on standards, and that they're chaired by such stellar women, who are going to be interacting with one another in linking the two groups together. I also just want to let you all know, if you haven't heard, Farzad Mostashari speak recently, it's just so wonderful that he is so committed on behalf of the whole organization to focus on consumer engagement and consumer empowerment. And he's articulated, even just within the last recent weeks at HIMSS for example, that consumer engagement is among the top three priorities for ONC this year. So, thank you for being part of pushing us forward in this area.

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

Well thank you Lygeia and thank you very much for your leadership. For those of you who don't know Lygeia, she has the privilege of leading the work at ONC around consumer eHealth and has done some fabulous work in the last couple of years around Blue Button, and the pledge program, and many other things. So, thanks Lygeia. So let's turn to workgroup members. You can see on the screen, for those of you who are logged in, that we have your name and your organization. So if we could just spend maybe 30 seconds each, since we have many, just describing a little bit about your organization and perspective that would be terrific. So we'll just go alphabetically, because that's easier. So let's start with Korey, from Healthinsight.

Korey Capozza – HealthInsight – Consumer Engagement Director

Hi everybody, it's Korey Capozza of Healthinsight. We're the Quality Improvement Organization for Utah. We're also a Beacon Community and an REC. My role here is I'm consumer – sorry, I just entered the online room and I got a lot of feedback there. I'm Consumer Engagement Director here and most of what I look at is how we can use technology to help consumers make better healthcare decisions. I come from a consumer health advocacy background. I previously sat on our state advisory board for our state health insurance exchange and I'm very excited to be a part of this group. Thank you.

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

Thanks and welcome Korey. James, are you on the line, I didn't think I heard you. How about Scott Fannin? Okay, I didn't think so. All right, so we talked about Leslie already. So Katherine, I know you're on the phone.

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

Hi, this is Katherine Kim. I'm a professor in residence at the Health Equity Institute at San Francisco State University and I'm a researcher and I do community-engaged research, primarily around health information technology and how it's used to help communities improve their health. In addition to that, I'm a PhD candidate at UC Davis in the School of Nursing and I'm doing my dissertation work on a model for consumer acceptance and use of technology to improve health.

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

Exciting. Thanks Katherine. Sarah? I thought I heard Sarah earlier, are you on mute?

Sarah Krug – President, Society for Participatory Medicine

Sarah, I'm here, sorry.

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

Okay.

Sarah Krug – President, Society for Participatory Medicine

So I'm Sarah Krug. I was just waiting for another Sarah to speak up, I wasn't sure I was the only one.

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

Sorry.

Sarah Krug – Society for Participatory Medicine – President

So, I'm Sarah Krug, I'm CEO of Cancer101, which is a non-profit based in New York City that helps patients and caregivers navigate the cancer journey and partner with their healthcare professionals to make informed medical decisions through a variety of tools. I'm also president of the Society for Participatory Medicine, which is a member-driven society whose mission is to catalyze collaborations among patients, providers and others across the healthcare spectrum to improve health. I have a clinical research background and formerly worked for Pfizer Pharmaceuticals.

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

Great. Thank you Sarah.

Sarah Krug – CEO, Cancer101 – President, Society for Participatory Medicine

Thank you.

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

Rita? Actually, Rita's not with us, sorry, I just realized that. So, Patricia MacTaggart?

Patricia MacTaggart, MBA, MMA – George Washington University

Hi, I'm Patricia MacTaggart, George Washington University where I'm another one of those connectors. I'm on the NeHC Board and the HIMSS Board, but I also teach under the ONC University-based Training, the graduate program for HIT policy and teach also in the regular graduate program HIT policy and state health policy. I'm a former Medicaid director, former HIPAA/CMS and spent a lot of my time, outside of teaching, working with states who are implementing health information exchanges.

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

Thanks Patricia. Beth, are you on, I believe so – no you're not actually. Have you joined yet? Okay. And I didn't hear Jan.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

Jan's plane got delayed and she has ended up in the air, is available on email, but that's about it.

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

Okay. Great. Thank you. Do we have Casey Quinlan? I don't think I heard her.

MacKenzie Robertson – Office of the National Coordinator

No we don't.

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

Okay. So Clarke, I know you're on the line.

Clarke Ross, DPA – Consortium for Citizens with Disabilities

Yes, I apologize, I'm on a cell phone and a moving automobile, but I'm not driving.

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

Okay good.

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

And I'll mute as soon as I get through. So, I'm Clarke Ross and I work for the American Association on Health and Disability, which is an organization of public health professionals who focus and concentrate on disability. For 25 years, I worked for three different family-based organizations in disability. I represent the Consortium for Citizens with Disabilities Workgroup of the National Quality Forum and I'm the father of a 22-year-old son with special needs. So thank you.

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

Thank you Clarke. Thanks for joining us while mobile, and welcome. Mark Savage?

Mark Savage, JD – Consumers Union – Senior Attorney

Hi, Mark Savage at Consumers Union. We're the non-profit publisher of Consumer Reports and I've been working in California to try to bring in the patient consumer voices into all of our work here in California, including being on one of the two consumer reps on the board of Cal eConnect, which is being supplanted by the new California Health eQuality Program with Ken Kizer at the Institute for Population Health Management. I've also been working with the state on various privacy and security issues around health information technology. I guess the last thing I say is that the folks I've been working with have been looking at this not only as the individual benefits for consumers, but also at a population or community health level as well. So thank you very much for inviting me.

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

Great. Thanks Mark. MaryAnne?

MaryAnne Sterling – Sterling Health IT Consulting, LLC – CEO

Hi everyone, I'm the CEO of Sterling Health IT Consulting, located here in the DC area. We specialize in health IT, health policy and communications. I'm working on several innovative projects to improve support for both patients and family caregivers. I serve as ambassador to Senator Mark Warner's office for the implementation of the National Alzheimer's Project Act and I do a lot of speaking in advocacy on behalf of other family caregivers. I have also been the co-pilot for my aging parents for the past 17 years.

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

Great. Thank you MaryAnne. Welcome. I didn't hear Ann Waldo, I don't know if she's joined yet.

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

Yes, I have.

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

Oh, great. Ann, do you want to go ahead and introduce yourself briefly?

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

Sure, you bet. Hi everybody, I am Ann Waldo with a boutique law firm here in Washington, and I represent some consumer-facing health technology companies, a good number of start-ups who are trying to do exciting things in this space. I have a consumer orientation, having done some pro bono work for consumer and patient groups and also been very much involved with PHRs and I am particularly passionate about patients having better access to their medical records and have done lobbying in that area. My legal specialty is privacy. I'm the former chief privacy officer of a global technology and of a pharmaceutical company. And I'm just delighted to be here.

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

Great. Thanks Ann. Ryan, I know you're on.

Ryan Witt – H4Y Corp

Yes, I am Ryan Witt. I'm currently working for a company H4Y, and we're connecting patients with clinical trials. It's actually an update to what's currently on the page, which is my previous employer, which was drchrono, they're an EHR company in the Bay Area and there I led meaningful use attestations and I also trained over 130 practices on our EHR platform and meaningful use. And prior to that I started and ran a non-profit that was focused on decreasing the diffusion of innovations in medicine to patients and doing that by empowering consumers to be more empowered legislatively and financially and then advocacy.

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

Great. Thank you Ryan and welcome. So we have a number of federal partners as well. Terry, do you want to start?

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

Sure. Thanks. I'm pleased to represent the Health Resources and Services Administration of the Department of Health and Human Services. We support and fund the Health Care Safety Net and I'm the director of the Office of Special Health Affairs under which we lead the coordination, the cross-agency coordination of health IT, quality, health equity and a few other things. And I also come to this committee as a healthcare provider; I'm a pediatric emergency physician. So, thank you.

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

Great. Thanks Terry. Cynthia?

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

Yes, I'm here. So I'm in the Office of Communication at the Centers for Disease Control and Prevention, and I lead the agency's work on health literacy and plain language. And I started at HHS back in the late 1990s and early 2000s with Mary Jo Deering, working on the early consumer eHealth projects, specifically the Wire for Health and Well-Being and have been involved in a number of projects over the years, trying to bring the health literacy and health communication insights to the health IT world.

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

Great. Thank you. Bradford? I don't think I heard him. Kim, are you on with VA?

Kim Nazi, PhD – Veterans Health Administration

Yes. Hi, this is Kim Nazi with the Department of Veterans Affairs. I work in the office of Informatics and Analytics and I'm actually completing my 30th year at VA. I had the great pleasure of serving on the AHIC's consumer empowerment workgroup and was very excited to see this new group stood up. I completed my PhD last May in sociology and my dissertation was focused on engagement and healthcare professional's experiences with patient use of personal health records and secure messaging. So I hope to bring that experience to bear. And most recently, I've been working pretty exclusively on the Blue Button, since its birth back in January 2010. So thank you for the invitation. I'm happy to be on the committee.

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

Great. Thanks Kim. Danielle, are you on?

Danielle Tarino – Center for Behavioral Health Statistics and Quality – SAMHSA

I'm here.

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

Great.

Danielle Tarino – Substance Abuse and Mental Health Services Administration

Thank you. My name is Danielle Tarino and I am pleased to represent the Substance Abuse and Mental Health Services Administration on this committee. I am a government project officer on SAMHSA's Health Information Technology team. I manage a grant portfolio that infuses health IT into direct behavioral health services. I'm also the lead for consumer education here on health information technology at SAMHSA. And also in a previous life, I was a strategic communications consultant where we used blogging, Twitter and Facebook to win elections.

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

All right. How interesting Danielle. Teresa?

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

Thank you. I'm Teresa Zayas Caban with the Health IT Portfolio at the Agency for Healthcare Research and Quality, where I lead the research strategy for the portfolio and also have led our grant initiatives related to consumer health IT. Our interest really is in understanding how these systems can improve quality of care. In the prior lifetime, I spent a lot of time in patient homes trying to understand how they manage health information, to help them with health management.

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

Thank you Teresa. Did I miss anybody?

James A. Cartreine, PhD – Brigham and Women's Hospital/Harvard Medical School

This is Jim Cartreine, I joined late, and I apologize. I was just getting out of a clinical session.

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

Okay.

James A. Cartreine, PhD – Brigham and Women's Hospital/Harvard Medical School

I'm at Harvard Medical School and Brigham and Women's Hospital. I'm a clinical psychologist and primarily doing research, which is actually primarily funded by NASA, to develop massively scalable behavioral health treatments. So the idea of having computers guide people through behavioral therapies that otherwise would only be available one-on-one from a psychologist. So, my work has been entirely on developing ways to treat problems that people might have either astronauts or else people in the general public, with computers. So, I have background in interactive media production as well. I also have a start-up that is commercializing some of the NASA work that we've done, especially a treatment for depression. The start-up is called Cognitive Behavioral Technologies.

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

You don't often hear references to astronauts or members of the public in the same sentence, that's pretty exciting stuff.

James A. Cartreine, PhD – Brigham and Women's Hospital/Harvard Medical School

Extraterrestrials and earthlings.

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

Right. Nice. Okay, good. And anybody else?

Erin Poetter Siminerio – Office of the National Coordinator

Christine, this is Erin.

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

Hey Erin, oh yes.

Erin Poetter Siminerio – Office of the National Coordinator

Hi. So, I'm Erin Poetter Siminerio at ONC and I'm going to be the staff lead on this workgroup. So I'm really pleased to be working with all of you. I've been at ONC for about three years. I work with Lygeia Ricciardi on our consumer engagement strategy and prior to transitioning into that work, I worked on the 5-year Strategic Plan for ONC and prior to that had some experience in the private sector working at Deloitte at their health services research center. So, I'm pleased to be with you.

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

Well, and we are grateful for all of your work in advance. Thank you.

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

This is Mary Jo Deering and I'm also in ONC, and I work in the Office of Policy and Planning with Jodi Daniel, where I lead the consumer and patient eHealth policy activities. And I have been doing this since before the dawn of the worldwide web, I hate to say. But I'm very pleased to see the dawn of this workgroup, because I think it's just a really major step forward.

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

Thanks Mary Jo. Anybody else? All right, well we have a stellar group assembled here with great and very diverse skill sets and expertise, so that's exciting. So let's take a second and talk about our charge and our scope. So our charge is really to provide recommendations on policy issues and opportunities for strengthening the ability of consumers, patients and family caregivers to manage health and health care. So that's our big picture scope...or our big picture charge, rather. Our scope is sort of determined as we go, based on other policy issues that are arising that we really need to have some policy around. We're going to talk a little bit about what those might be, but there's a lot, as you know, right now on issues like patient-generation of their health data, care plans and how patients might contribute or author or co-author them. Patient reconciliation of medical records, that's particularly timely, given the fact that in the next phase of meaningful use, consumers are going to be able to not just go online to view their own health record, but download it. And so if I have three different doctors, I could potentially have three different sources of health information and reconciling errors across them becomes a real issue. So, there are also, of course, new types and sources of patient data. So any or all of those could be examples of policy issues that might be in our scope.

And I emphasize policy because we're not the technology folks that will be Leslie Kelly Hall and her incredible workgroup on the Standards Committee. But we'll have a lot of interaction with them, in particular, as well as with other workgroups. So, I've listed a couple here and actually, we've asked MacKenzie to give us kind of an org chart of the Health IT Policy Committee, if you will. But as you know, there is a Meaningful Use Workgroup that we may touch, in which case we would do a hand-off around...or make a recommendation to them around some of the issues. They may also be handing off policy issues to us. But the example there, our job is not to create meaningful use requirements, that's the Meaningful Use's Workgroup, but we could recommend them to the workgroup if we needed to, or came across them for some reason. So, there's lots of great touch points to other groups. But I'll turn it over right now to MacKenzie, who is the FACA Coordinator, and does a terrific job for ONC. And she's going to talk about the processes and procedures for federal advisory committees, for those of you who don't know the FACA language; it's the Federal Advisory Committee Act, which is the legislation that governs how public workgroups like ours operate. So MacKenzie...

MacKenzie Robertson – Office of the National Coordinator

Thank you. So, good afternoon again everybody, I'm MacKenzie Robertson, I'm the FACA Program Lead within ONC and I manage both the HIT Policy Committee and its workgroups and the HIT Standards Committee and the workgroups under that one. I just wanted to set the scene for you guys in terms of the workgroup and the process and procedures for how the workgroup will function, both within the HIT Policy Committee and then just administratively going forward. So, the Consumer Empowerment Workgroup is a workgroup under the Health Information Technology Policy Committee and the HIT Policy Committee is a Federal Advisory Committee, subject to the Federal Advisory Committee Act, also known as FACA. So, you'll hear that word a lot in the workgroups.

The Federal Advisory Committee Act is a statute that controls the circumstances by which the agencies of the federal government can establish and obtain advice or recommendations where one or more of the members of the group are not federal employees. So it's really gathering advice from the public and the HIT Policy Committee is charged with making recommendations to the National Coordinator for Health IT on a policy framework for the development and adoption of a nationwide health information infrastructure, including the standards for the exchange of patient medical information. And just as I said, the Committee makes recommendations and provides advice. The recommendations are obviously taken into consideration by ONC, but they are not binding in any way.

So the workgroups themselves provide advice or recommendations directly to the HIT Policy Committee. The workgroups cannot provide advice to ONC directly, so any recommendations that you do discuss within the workgroup need to be presented back during a full Committee meeting of the HIT Policy Committee. ONC also values public input and has made it policy that all the workgroup meetings are to be open to the public, and that the public is able to provide comments at the close of each workgroup meeting. That is not actually a requirement by the Federal Advisory Committee Act, but that's how much ONC values the public input.

In terms of the workgroup calls, the majority of them are held virtually, similar to how we're holding this one now. We also may have in-person meetings if we feel the need arises. You also have the option of holding listening sessions, which allows you to invite members of the public or invited experts to come and testify and give input to the workgroup directly, or we can hold full, in-person hearings, where you can hold multiple panels throughout the day to address any additional questions that you need input on. In terms of administrative matters, we have detailed minutes that are kept for each meeting, and they are posted up on the ONC website, so they're usually available a few days after the workgroup call. All the workgroup meetings are also posted up on the ONC website and there is information for the public to join in and participate on the ONC website as well.

And in terms of the workgroup appointments, all official calendar appointments and any meeting materials for the workgroups will be distributed from the ONC FACA meeting email account. It really helps keep us organized in terms of everyone can look for the same email account for the materials for each meeting. And then next we have the org chart for the HIT Policy Committee, and the Chair of the Policy Committee is the National Coordinator, Dr. Farzad Mostashari and the Vice-Chair is Paul Tang. It also lays out all the different workgroups that are currently active for the Policy Committee. So right at the top is the Consumer Empowerment Workgroup, and then we also have the Certification and Adoption Workgroup, the Governance Workgroup, Information Exchange Workgroup, the Meaningful Use Workgroup, Privacy & Security Tiger Team and the Quality Measures Workgroup. And I've also listed the Chair and Co-Chair role for each of the workgroups.

And on the next slide is the org chart for the HIT Standards Committee. That's chaired by Jonathan Perlin and vice chaired by John Halamka. The Consumer Technology Workgroup is right up there at the top and that's chaired by Leslie Kelly Hall, who's also a member of this workgroup. We have the Clinical Operations Workgroup, the Clinical Quality Workgroup, the Implementation Workgroup, the Nationwide Health Information Network Power Team and the Privacy & Security Workgroup. So that's just going to give you an overview of how the two committees are structured and each of the active workgroups underneath. So with that, I'll see if anyone has any questions. Okay, I will turn it back to you then Christine.

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

Well MacKenzie, let me ask you, I guess, the basic question which is for the group, for those who haven't been part of a workgroup before, could you describe kind of the tools that we have available to us. So we're going to meet on a regular basis and talk and either you guys or other workgroups are going to ask us to take on some policy issues that...where we really need to make progress. But beyond that, in order to facilitate those discussions or really help our thinking, we see other workgroups doing public hearings, for example or sometimes a FACA blog, can you just give kind of a quick preview of those?

MacKenzie Robertson – Office of the National Coordinator

Sure. So as I just briefly mentioned before, you have your routine workgroup calls, which will be scheduled monthly. But if you do come up against a charge that really needs some outside input, you're more than welcome to hold either listening sessions, which are just longer workgroup calls where you can invite experts in the field to come and present to the workgroup, to give you any more additional information to handle the task that you receive. The next step up from a listening session is an in-person hearing. This tends to be a day long. They probably have four-to-five panels throughout the day, and you can ask specific questions to each panel and they usually consist of four-to-five panelists, again, invited experts that are brought in to provide testimony to the workgroup, to help them in their deliberations for any recommendations they'll be working on to present to the Policy Committee.

We also, if you visit the healthit.gov, there is a blog and we are more than welcome to post a blog posting up there, we can ask for public input. We do have the public comment portion of each agenda, but if we feel that we're not getting enough public input, we could do a blog posting and ask specific questions or inform members of the public of what we're working on to see if we can get some more public input that way.

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

And I think in terms of like an RFC, you know, we kind of try to avoid those I think, because it's pretty intensive, but that's really mostly something that maybe the Meaningful Use Workgroup does.

MacKenzie Robertson – Office of the National Coordinator

So, the Policy Committee itself put out an RFC a few months ago regarding Stage 3. They are very labor intensive, but it is an option that is available. The workgroups in the past I believe for Stage 1 and Stage 2, an RFC, which is just a Request for Comment for those that don't know, we – it's a way to gather more formal public input. We use regulations.gov website. So we can do that, we do have the option of doing it at the workgroup level, but it is very labor intensive.

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

Right and we would only really want to do that in conjunction with the Policy Committee's ...

MacKenzie Robertson – Office of the National Coordinator

Right.

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

Okay great. Thank you. So, any questions for MacKenzie? All right, terrific. Thanks MacKenzie. All right, so what I thought we would do next is, I'm going to do a superfast overview of some of the Meaningful Use Patient and Family Engagement criteria, just as a reminder for what's out there or what's changing our landscape now and in the immediate future. It's also the stuff that we won't take up because that's in the purview of Meaningful Use, but they do raise some policy issues, the example that I described earlier. So I thought just to levels that I would do that, and then we're going to ask Leslie Kelly Hall to talk a little bit about the S&I Framework, the Standards & Interoperability Framework, which has been doing a lot of work around things like care plans and other things.

So I'm going to go pretty fast through this, because I assume that you guys are mostly familiar with it and if you're not, you can certainly read an enormous amount about it on CMS's website through their tip sheets and others. So, in the Stage 2 Final Rule, you will recall that probably the centerpiece of patient and family engagement is something called view, download and transmit, or VDT for shorthand. And that's going to allow patients to go online and not just look at their health information, but actually download it and potentially send it either to a secure place of their choosing, like a personal health record, or to their cardiologist, for example. And this is the one that does have a use requirement in there, and so eligible professionals and eligible hospitals are both asked to make sure that more than 5 percent of their patients have actually logged on once in the reporting period.

Another major advancement, which was actually part of Stage 1 as well, and it's been a core objective since its inception, is the idea of clinical summary for patients for the office visit. So, that is when you leave the visit, you get a snapshot of what just happened, what the diagnosis is, when your next appointment is, any kind of pending lab results or test results, things like that. We did add some things to it, the Policy Committee did recommend that and then CMS and ONC did, for Stage 2, which would be care plan fields, which is really goals and instructions, as well as a list of care team members, although I think that's on the care summary for docs. So, I may take that back. Anyway, so the next one was patient specific education resources. So in Stage 2 this was the ability to use the EHR to automatically identify education resources that would really be relevant to that particular patient. Not sort of a global resource, but this is appropriate for me because I'm a woman, I have diabetes, I have this and I have that and so that's a resource that I may need.

And then secure messaging. So this is the idea that now you can actually send a secure email to your provider, who can reply or send one to you. And so again, there is a use function on this one, which is more than 5% of patients are actually encouraged to, and actually do, in the reporting period, go through and send at least one secure message in that 12-month period. In Stage 3, there was a Request for Comment asking the public to weigh-in on a couple of advancements and changes. And I'm going to give you a very fast preview of that, because lots is changing as we go forward. But, this is a particular piece of Stage 3, which is the care plan component. So I mentioned that in Stage 2 ONC and CMS did add some elements of a care plan to two places, one was the office visit summary that I just described, but the other was a clinical summary that goes from provider to provider, and they did add the patient goals, instructions and also the secure team members to that. So, one of the things though that we really struggled with in the Meaningful Use Workgroup was how you could advance care plans well beyond that basic functionality. And so there was a question in the RFC that we asked around how we might get to a stage where we can have more robust care planning.

And this is... what you see on your screen is the objective that was actually proposed for a future stage, not necessarily Stage 3, but some later point. And the idea was that any time a patient is transitioned to another site of care or if they're referred to another provider, that a care plan would be provided that had the elements you see on the screen. There are some important additions like functional status, including activities of daily living, relevant social and financial information, which again is probably free text, some environmental factors that would affect patient's health, most likely course of illness in broad terms for them. Let's see, the patient's long term goals for care including their timeframe and initial steps for meeting those goals, and adva – the physician orders for life-sustaining treatment, which is a kin to Advance Directives, something that indicates what their end-of-life wishes might be.

So it would be a much more robust care plan. But what that really triggers is a whole set of questions that we think this workgroup would be very good at taking on. It's an enormous first task, but I think we can do it, which is around – so if we think about this concept of a shared care plan, whether this is how you define it or not, patients are going to want to contribute to that care plan. They're going to want to maybe even drive the care plan. Some will want to create their own goals that are really oriented more towards their life circumstances and then have clinical judgment and treatment recommendations support achieving those. How do you update progress on a care plan, etcetera? So there are lots of policy issues to discover here. And on the next slide, you can essentially see that I just described it. How often do we share updates for the care plan?

So, what I'd like to do at this point is turn it over to Leslie to give a quick overview of the S&I Framework, which does have a significant focus on care plans, so she can describe that work, in terms of the work that has been done to create some standards around care plans. And then let's have a conversation. So let me acknowledge two things up front. One is there's no actual standard definition for all the types of information that would go into a care plan. There's no template. But we did this work a couple of years ago to try to figure it out, and there's lots of examples of care plans, it's definitely not a new concept, but no one agrees as to what it is. I will also say that meaningful use is a pretty medical model and probably nobody on the phone knows this better than Clarke Ross, who can talk about how the disabilities community and individuals with disabilities really look at care planning in a completely different way. They call it person-centered planning, so that it's not patient-centered care plan, it's person-centered planning. So, there's been a lot of work done though to try to create at least some standards that could support the kinds of data elements that might be needed. So Leslie, I'll turn it over to you to talk about that, and maybe you could start with a 101 on what the S&I Framework actually is.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

Sure, thanks Christine. So, I'll talk a little bit about all the standards work. The S&I Framework is actually a structure that has been done in support of ONC to establish a consensus-based approach to determine the technical standards required to meet the policy needs of meaningful use and beyond. And along with the S&I Framework, we also see many other standards bodies working together or working in concert to also advance the needs that have been shared under meaningful use and beyond. So I'll speak to a few of those. One of the common threads that our Chairs, Jonathan Perlin and John Halamka talk about often is parsimony. And that is to make sure that anytime we work on standards, we get a two-fer or a three-fer, we get as many possible opportunities for use and opportunities for meaningful use with every standard that's developed.

So some of the things that are being worked on today are, as Christine mentioned, view, download and transmit, also publish and subscribe, the idea that not just transmitting to an individual or to a doctor from another doctor. But actually be able to publish or have an application assigned to receive that information as updates occur, and hopes in the future that include subscribing – excuse me, I have that backwards – subscribing, which would give you the ability to have an as attached, or publish, to be able to update or put information back into the record, which is just now starting. And I've – my Internet just dropped at the airport, so, one second. The other things that we're working on a – and, let's see if I can get back in – the view, download and transmit. We also have talked about care planning and the long-term post-acute care or the longitudinal care team record work in S&I Framework has also helped contribute to the care planning structure. It's still very new and I'm afraid it has lost me.

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

Leslie, I can tell you, you have patient generated health data HL-7, C-CDA ...

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

Yes, um hmm. So patient generated health data and I'm afraid I've been logged out of this workgroup so, I'll have to log in again. But thank you, yes, the patient-generated health data, we have several groups working on that. One is ONC has sponsored an effort with NeHC, the National eHealth Collaborative, to help to study, see what's available and to make recommendations that will end up coming to this team, about patient generated health data. What are the opportunities for use? How prevalent is it? What is the structure in place? We hope to continue that standards work that's been started. In the HL-7 team, the patient generated health data, which was just completed or voted upon and been in HL-7 in February of this year. So we're excited, it's the first time we have a structure, it also uses the Consolidated CDA and it helps supply the opportunities for parsimony. What's the next one Christine?

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

The roles and team members ...

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

Yes. An important component of care planning is to have a common concept of who participates in care planning, from the patient and their caregivers to the professionals in place. And we were encouraged by some of the work that CDISC has been doing and have used that information to help inform the work under the patient generated health data team within HL-7. So, we're seeing a lot of cross-pollination of efforts being done across standards organizations to create parsimony and we hope easier adoption and use. Any others on the list?

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

Enroll in clinical trials research.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

Oh, that also has been very exciting. Part of the Meaningful Use 1 and 2 requirements under patient specific education materials defined a shared context around the patient and the provider that would allow an electronic health record, at the point of care, to be a query externally to see what available information is in the ecosystem that would help in shared decision-making, clinical decision support, and patient education materials. Most recently has been advanced by CDISC as a way to look for available clinical trials and enrollment in those trials. So, in the standards group we seek to see how many reuses we can get of an existing standard so that the things become widespread, they become easily adopted and also provide opportunities for innovation.

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

And then the next one is Direct, to/from provider, consumer and team.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

Okay. So as all of you I'm sure are aware, Direct is the standard that's been identified for communication between providers. And I also chair a workgroup under DirectTrust.org where we're looking at expanding that to include patient to provider, provider to patient and other, so that each of us has our way to communicate with a provider in a true way that's consumable by the EHR and actionable by the physician. So we're very excited to expand on the work being done in the Blue Button initiative and also in Direct.

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

Great. And the last one is shared decision-making interoperability, IOM, HL-7.

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

Um hmm, yup. So the Institute of Medicine has convened a group, I think over a couple of years now that has been looking at shared decision-making. Lygeia and I had a chance to participate in that, I think Patricia might have been part of that too, last month, and we're looking at using that same standard for patient education and shared decision-making, so that we can...that providing information at transition, that allows the patient to share in decision-making with their provider, so that they're getting the best possible opportunities for care or to say no to unnecessary care. So, that work is being done, I believe a white paper will be issued from the Institute of Medicine sometime in the next year regarding that. So, in each of these areas we're looking for parsimony and adoption and ease of implementation.

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

Great. Thank you so much Leslie. So, we've been talking at you for a little while, I'm sorry about that, that'll be unusual for this group. But, we wanted to now turn it open to the group and get your reaction to this idea of taking on some of the policy issues around shared care plans. I would imagine that that would include things like what content of a shared care plan is important to consumers, for consumer empowerment, and what are the policy issues and recommendations around consumers' ability to contribute to those plans, to update them, to share them and use them in other ways? That's broadly speaking, kind of my take. But let me open it up to the group and get you guy's reaction, any issues that you want to make sure we cover things like that.

Mark Savage, JD – Consumers Union – Senior Attorney

This is Mark Savage. I want to go back to your comment Christine, about the different perspectives on what a care plan might include, whether it's patient-centric or person-centric, Clarke's comment, to ask more generally, is this sort of a modular effort where the standards are broad enough to work with different kinds of care plans that people coming from different backgrounds might like to have? Is there room for modularity or flexibility within a standards-based approach?

Leslie Kelly Hall – Healthwise – Senior Vice President, Policy

This is Leslie. I could take that Christine if you would like, and yes, there is. The goal would be that a standard actually encourages flexibility rather than becomes prescriptive. We want policy to be the what and the standard to be able to accommodate the how.

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

So I think, and ONC staff will jump in if I'm off on this, but I think it's a really...there's an important kind of question around that is more of a policy question that you're raising Mark around how do we make sure that care plans are appropriately tailored and flexible and modular. In other words, we don't want to lock the technology into, well this is what a care plan template is, because my care plan and I'm not somebody with a host of chronic conditions, but I could have one, would be very different from someone who has chronic conditions or who has disabilities or whoever. So, how do we make them modular and adaptable to individuals, and not lock them into technology. And I think what Leslie's saying is, there are...the technical standards approach does need to be modular. But I think it's an open discussion in terms...but I haven't heard anybody in the Policy Committee take on, in terms of that it even is a flexible, kind of modular approach, that there are different types of care plans.

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

Well just to add on one example, my understanding is that there would be cultural differences in different populations around what they would like to see in a care plan and how they would like it to work for them and their immediate caregivers. So, it seems like it would be an important function to build in.

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

Yeah. Great point.

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

Hi Christine; this is Clarke.

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

Hi Clarke.

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

I think they focused on person-centered planning, participant-centered planning, just one other complexity to add to this. People with disabilities in the community are highly reliant on social, community-based, non-health, non-medical organizations and this is an essential ingredient to their life planning goals that adds to the complexity of health IT and a health system providing, and that's an issue that we'll have to grapple with. I'm sure that Danielle with SAMHSA can amplify that kind of challenge from the peer perspective. So, I just wanted to add that issue and element for further discussion in the future.

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

Yeah, I think that's right. Thanks Clarke.

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

This is Terry. I just wanted to – the previous speaker had brought up being sensitive to different populations. Being a pediatrician, I think something you may want to put on your list for consideration would be any possible differences in a care plan based on age, children versus older people. And secondly, take into consideration transition to adulthood, which is a very big issue for care plans in pediatrics.

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

Great. Thanks Terry. Got it.

Patricia MacTaggart, MBA, MMA – George Washington University

And this is Patricia. I would second everything everybody said and just add two elements is transition not only by age, but by care delivery system, in and out of corrections, juvenile justice, things like that. And the second piece is to make sure that we're thinking about shared care plans with the health care delivery systems that we're moving to versus the ones that we're living in, because the new ACOs, the new coordinated care plans, really are doing integration of behavioral and physical health, integration of long term care and acute care, and that's a very different thought process than the traditional care plan that we've lived with.

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

Right.

MaryAnne Sterling – Sterling Health IT Consulting, LLC – CEO

Hey Christine, this is MaryAnne. I want to echo Clarke's comments and also toss in a few specifics from the family caregiver perspective. I would hope that one thing that we can help address here is to make sure that our care planning efforts incorporate things like social services and community supports that are so siloed from the care delivery system today, and make sure that we integrate those together, as we're looking through the lens of care planning.

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

Great. Thank you.

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

Hi, this is Kathy Kim and I think this is a great first task to take on. I'd like to add into our list of things to consider, that shared care plans really need to be community-wide, and you've already mentioned sort of transitioning provider and receiving provider. But as other people have said, there are community organizations, there are families, there are social services and that there's a whole set of workflow and communication and the idea of, this is a social network that we need to consider, that goes beyond an EHR. And so how, if we're focused on EHRs do those EHRs actually communicate and collaborate with other technologies that people actually use, that consumers actually use, on a daily basis.

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

That's a great point and I think the good news is meaningful use is stuck in an EHR construct, I'm not sure we have to be, and I don't mean the stuck reference pejoratively as that's what the law says. But we could actually look at care plans as a way to create that bridge so that it actually introduces some efficiencies and support for providers by having their EHRs make those connections. Other thoughts? I know we only have a few minutes left, but so far I'm not hearing anybody say, this work has been done before, we don't need policy on it – is there anybody that wants to share that view or add anything to the discussion that we want to keep considering?

Danielle Tarino – Substance Abuse and Mental Health Services Administration

This is ...

James A. Cartreine, PhD – Brigham and Women's Hospital/Harvard Medical School

This is Jim Cart ...

Danielle Tarino – Substance Abuse and Mental Health Services Administration

Thanks. This is Danielle from SAMHSA and I just wanted to add in really quickly the issues that we had here at SAMHSA surrounding consumer education and engagement. We found on some of the webinars that we did that had very low levels of participation that generally the populations of people that were attracted to those webinars were already people in professional fields and we have tremendous difficulty reaching the everyday consumer.

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

Okay. Great. Thank you Danielle. Jim?

James A. Cartreine, PhD – Brigham and Women's Hospital/Harvard Medical School

Yeah. Just coming from a mental health perspective, it's always a little bit strange and tricky how mental health gets handled in large health care organizations. One piece of it is that most mental health disorders, at least in terms of non-debilitating problems such as depression and anxiety, are handled in primary care. Nonetheless – and so those – and health information for the primary care providers is tracked in a standard way. However, once they come to our service, which is the Department of Psychiatry, we have kind of a firewall around our medical records and around our ability to share information, even to the point where a medical records release doesn't cover our medical records. And so, I guess that's just something to be aware of, that the care plans developed for mental health patients are treated somewhat differently from patients in other services.

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

Okay. Yeah. So think something around how our – I mean, it's really a sensitive health information issue, so it's sort of care plans that contain sensitive health information?

James A. Cartreine, PhD – Brigham and Women's Hospital/Harvard Medical School

Yeah, and my impression is that it's more a concern among mental health care providers than among patients. But nonetheless, that's kind of how it ...

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

Yeah, but I think it gets to some of the issues around sharing and who makes the decision and how do you record that decision and for what purpose, which that we'll touch up against the work of the Privacy & Security Team. But I actually think they've done some work that would be very helpful to us here. But, so that's a good thing to flag Jim. Okay. Anybody else have a burning comment they want to make.

Kim Nazi, PhD – Veterans Health Administration

This is Kim. I just appreciate that you framed this as a dynamic entity so that as things change, whether it's the patient's circumstance or their preferences, that that change ripples out so that we don't have documentation lost within a system and that the patient truly is kind of the driver of those updates, so thank you.

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

Yeah. So, I think – on that note I'll say that there – one of the things that the National Partnership does, my organization, is we believe in bringing more and more consumer organizations to discussions like these. And so we actually started a discussion a while back with a number of consumer organizations around care planning, which turned out to be very timely when ONC had this idea for starting with shared care plans. They have come up with some draft – there are some draft principles that would touch on a lot of these points, so it may be worth really sharing those with the group as we go forward.

But speaking of going forward, so what we're going to do, we will schedule a meeting for the next month and we're going to do a couple of things on that call. One is we will begin to dive into these care plan issues and continue this discussion, and I'll work with Erin and the team at ONC to come up with some ideas for how we can start to capture these ideas and think about other inputs that we might need. And then I think it would be very useful to have a briefing from ONC for about 30 minutes or so, on some of the other projects that they're working on, that are going to raise some policy issues that we may take on sequentially, and address in the future. So, with that, any last comments or questions, before we let you go, because we are at the witching hour?

MacKenzie Robertson – Office of the National Coordinator

Well, we'll need to open it for public comment, too.

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

Well yes, I didn't forget – okay, I might have forgotten. MacKenzie, do you want to open for public comment?

Public Comment

MacKenzie Robertson – Office of the National Coordinator

Sure thing. Operator, can you please open the lines for any public comments?

Rebecca Armendariz – Project Coordinator, Altarum Institute

If you would like to make a public comment and you are listening via your computer speakers, please dial 1-877-705-2976 and press *1. Or if you are listening via your telephone, you may press *1 at this time to be entered into the queue. We have no comment at this time.

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

All right. Terrific. Well thank you all again, it was a good, terrific first discussion and we will look forward to having even more discussion next time and we'll be in touch soon. So thank you again.