



Collaboration of the Health IT Policy and Standards Committees

Consumer Task Force

Final Transcript

May 16, 2016

Presentation

Operator

All lines are bridged.

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

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

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Present.

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

Hi, Donna. Patty Sengstack?

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Hi.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

I'm here.

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

Hi, Patty.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

Hi.

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

Allie Foti? Angela Kennedy? Brian Ahier? Carolyn Kerrigan? George Mathew? John Derr?

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

Here.

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

Hi, John. Kevin Fowler? Leslie Kelly-Hall?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Here.

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

Hey, Leslie. Susan Brown?

Susan Brown – Health IT Director – Telligen

Here.

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

And Suzie Hull?

Susan Hull, MSN, RN – Chief Nursing Informatics Officer – Cincinnati Children’s Hospital Medical Center

Present.

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

Hi, Suzie. And from ONC do we have Lisa, Liz and Margeaux? Anyone else from ONC on the line? Okay, well we have a small group for our first meeting, but small but mighty we will be. And so with that, I’m going to just turn it over to Donna and Patty to do a few quick introductions.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Sure. This is Donna Cryer; I just wanted to say thank you for everyone who did volunteer for this very important work on the Consumer Task Force and made time today to be on this call. We will, I’m sure, make attempts to reach out to the other members who have been named to this task force and I look forward to robust engagement and input in this very short and consolidated timeframe that we have to be able to provide feedback on important issues.

For those of you who are not familiar, I make no...I have no assurance in anyone but my mother, knows my name or...me before but I have the privilege of being the patient consumer representative to the HIT Policy Committee. I am a liver transplant and IBD patient and run the Global Liver Institute and Chair the Society for Participatory Medicine. And so, perhaps we’ll give a few moments for sort of one-line introductions and I’ll certainly turn this over first to my Co-Chair, Patty Sengstack to introduce herself to this group.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

Well thank you, Donna and hello everybody. So again it's an honor to be leading this group, and I know I'm looking at the slides now and it says Patricia, but please call me Patty; and I am currently the Chief Nursing Informatics Officer for the Bon Secours Health System. So we're based in Marriottsville, Maryland, but we have hospitals up and down the East Coast and I always say that's a good thing because we're all in the same time zone. So, that helps.

I'm the former Chief of Clinical Informatics for the NIH Clinical Center and I also serve on the Informatics Faculty at Vanderbilt University. And I've been working with the electronic health record since, gosh about 2...the year 2000, so I feel like 15 years have kind of taught me a lot not only in terms of what, you know how nurses and physicians interact with the systems, but how our consumers might interact with it as well, and I think we have a ways to go there. So hence this group getting together; so looking forward to our work.

So do we want to...I'm looking at the slide, do we want to just kind of go down the list in order and have folks just kind of give us a quick introduction of themselves as part of our introductions here? So Suzie Hull would be next.

Susan Hull, MSN, RN – Chief Nursing Informatics Officer – Cincinnati Children's Hospital Medical Center

Thank you Patty and Donna; I also am a nurse that has been passionate about consumer health and engagement for probably most of my career. Early on in my career I was part of a group in San Antonio, Texas who built a Healthy Community Partnership and I then subsequently served as...Executive and we tried to build a community health information network, thinking about the information exchange and sharing needs, particularly for consumers, but also for providers. So that was, you know going on 23 years ago, being quite passionate about this.

I also Chair a task force with our...one of our sister organizations in nursing informatics called the Alliance for Nursing Informatics around consumer eHealth. We were part of the early Blue Button pledge community. I've served on the Consumer Technology Standards Workgroup for the HIT Standards Committee and also the Content Standards Workgroup and a short stint with the NeHC consumer eHealth advisory group; so very pleased to serve.

I've recently moved to Cincinnati, Ohio where I'm serving as Chief Nursing Informatics Officer here and we have a great body of work to do in this area, particularly around children and parents, as well as community sharing and exchange of access to health information. So thank you.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Thank you. So...

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

I think the next person on the call is Susan Brown.

Susan Brown – Health IT Director – Telligent

Okay, hi.

Brian Ahier – Director of Standards and Government Affairs – Medicity

I'm sorry; Brian Ahier is on the call.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Oh, okay, great Brian. Glad to hear you.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

Hi, Brian.

Brian Ahier – Director of Standards and Government Affairs – Medicity

(Indiscernible)

Kevin Fowler – Consultant – Kidney Health Initiative

Can you hear me, guys? This is Kevin Fowler.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Ah...Kevin.

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

We can now.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

Kevin; we can now.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Excellent.

Kevin Fowler – Consultant – Kidney Health Initiative

Yeah, I've been here the entire time, I apologize; I just was having challenges with audio, so glad to hear that people could hear me. So, I've been here the entire time, so.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Oh, okay.

George Mathew, MD, MBA, FACP, CMQ – Medical Director, Quality Measures & Analytics – ActiveHealth Management/Aetna

Hi, I'm George Mathew joining the call; sorry I came in a little late, didn't want to interrupt anybody.

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

No, that's great; we're glad more people joined. So this is wonderful.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Yes.

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

So we'll go down...we'll start with Brian.

Brian Ahier – Director of Standards and Government Affairs – Medicity

Great. Well thanks, yeah this is Brian Ahier; I'm the Director of Standards and Government Affairs at Medicity, which is a healthagen business within Aetna and served in a number of capacities over the last few years on other workgroup and task forces within the ONC, governance framework and, you know between the HIT Policy and HIT Standards Committees. I'm also involved on a number of HIMSS workgroups and committees, HL7 workgroups and committees, CHIME workgroups and committees and other standards development and, you know workgroups particularly focused around the patient, is sort of a passion of mine, is having the patient really involved as a member of their care team.

And, you know, most of the efforts so far have been in clinician communication and care coordination among clinicians, which we've made some great progress with. I'm hoping to see us really move now, in the 21st century, to having the patient involved in that health data exchange and population health management ecosystem. Thanks.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Excellent.

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

Thanks, Brian. Susan?

Susan Brown – Health IT Director – Telligen

Okay. Hi, I'm Susan Brown from Telligen and I'm located in West Des Moines, Iowa. I have worked on several ONC programs. Most recently I was Director of our state's Health IT Regional Extension Center. I'm also on the Board of our state HIE. And I bring a caregiver perspective to the table. I have three kids who are adults, but they have a genetic syndrome that will require lifetime care; so I've got a lot of experience with the healthcare system and I can balance that with what I know is possible from an IT and service delivery standpoint. So I look forward to participating.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Okay, who's next on our list?

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

Kevin Fowler would be next, next one.

Kevin Fowler – Consultant – Kidney Health Initiative

Yeah hi, and glad first of all everyone can hear me, so, and also be glad to be here as well, too. Just some background for myself, just professionally and personally. Professionally I, you know my career was spent in the pharmaceutical industry, working in both commercial and R&D and then towards the end of the career in Pharma I worked in patient marketing and so I had a lot of experience with patient engagement strategies. And then on a personal level, you know I have very much of an extensive patient journey with the healthcare systems around experiences through having a kidney transplant and also

there's been a couple of complications that have followed from then that have...are just an aspect of having a chronic disease.

And so I have a lot of firsthand experience with shared decision making, very positive experiences; also in terms of patient engagement, you know, my perspective on healthcare is that healthcare is not designed for the patient, so I bring that perspective to it. And I'm also involved with, you know, multiple different organizations, the Kidney Health Initiative, American Society of Transplant a patient advocacy group and just a number of different areas, so, I guess I look at this from multiple perspectives, but ultimately I look at it from the perspective that we have a healthcare system that's not designed for patients and I look at how I can contribute to change so that healthcare...for and by patients. So that's my perspective.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Excellent. Leslie Kelly Hall, who really, truly needs no introduction in this landscape, but.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Thanks, Donna.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Hi.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

I'm Leslie Kelly Hall; I'm with Healthwise and the Informed Medical Decision Making Foundation. I sit on the Standards Committee and many other committees involved with ONC. I'm a former Chief Information Officer of a health system in Idaho where we connected seven hospitals, 95 physician clinics and others to create a repository of 12 years' worth of history and provide that to the patient across all those organizations since 2003 where we had to sign-up almost every six seconds. So we know the value, know the value firsthand of...the information.

But I switched careers when a patient called me crying saying that she hated...because she got online and saw that her physician calls her a "difficult, middle-aged, chronically...chronically difficult, middle-aged morbidly obese woman" in her record and she had no idea what morbidly obese meant until she went online and she called crying saying that her next visit to the doctor would take her family with her so that she could...grandchildren. And with that call, really discovered how important access to information was and that patient education was paramount as any patient...so that...that's it; happy to be here, this is a great group. I'm really excited about what's to come.

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

Thanks, Leslie. I think the next person on the call is George?

George Mathew, MD, MBA, FACP, CMQ – Medical Director, Quality Measures & Analytics – ActiveHealth Management/Aetna

Hi, everyone. I'm George. So I'm an internal medicine doctor. I'm the Chief Medical Officer for Hewlett Packard Enterprise Services and again, we're just trying to help make things better, if that's possible. I used to do Quality Measures over at ActiveHealth over at Aetna; so...Medicity folk I hear Brian on the...one of the earlier people, we never really got to work together, but we overlapped with similar people. Again, this is my first ONC committee, so I am grateful you invited me.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Welcome. John?

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

John.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

John Derr...my name is John Derr; I'm a pharmacist. I've been in healthcare for over 50 years; head of Squibb product development, head of Siemens Ultrasound/Nuclear Medicine, Senior VP for Tenet; started four companies. Most recently I was the Executive VP for American Health Care Association and CIO of Golden Living, which has 63,000 people under their care. It's a LT...long-term post-acute care.

I'm with JD & Associates where I'm a strategic advisor; 2009 when...or 2004 when Secretary...or President Bush did the Executive Order for digitizing healthcare, Secretary Thompson asked me to coordinate long-term, post-acute care. I formed the Long-Term Post-Acute Care HIT Collaborative, which has all associations that are associated, sorry for the use of the word...with long-term post-acute care. I've been on the Standards Committee since 2009. I'm on two CMS grants. I'm on a number of other state and federal committees all representing long-term and post-acute care. I've been an advocate for person-centric longitu...electronic longitudinal records for years and also person engagement.

I happen to be a, whether I'm sorry or not, but I am one of the chronic care people that have fallen under the CCM Program. And in fact, just today I was over at a doctor's office and reminded him that I needed a CBC on Friday and he said, "oh, thank you very much." So, patient engagement to me is the only way that this whole system's going to work. I know it'll take a while, but anything we can all do to hurry it along, I think will be very important. Thank you.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Excellent.

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

Thank you, John. I think John was...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Is there anyone else...joined the call since...

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

Sorry.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

...this is Donna. So has anyone else joined the call since we started making introductions; otherwise, I think we have everyone. I just...for those who joined the meeting perhaps a moment after, I just wanted to reintroduce myself; I'm Donna Cryer. I have the honor, with Patty, of being Co-Chair of this committee. I am the patient and consumer representative to the HIT Policy Committee and I thank you,

in advance, for all of your hard work, robust contributions and conversations. This really is...I appreciate the help of the ONC staff members in helping us put together what is clearly a very diverse, super-team of a consumer health task force to help us answer the charge that I will now let Michelle and others explain to us and present to us.

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

Thanks, Donna. I do want to note that Lana Moriarity is actually the Staff Lead for ONC. She's traveling right now so she got people to join; so we have a number of other ONC folks on the line that are going to help walk through the charge for this task force during today's call.

So I think as hopefully most of you all know this task force is going to function just a little bit differently than some of the others that we formed. Our goal behind this task force is to form a core group of members, which is all of you, who can provide ONC with insight on projects or initiatives you know, anything with a consumer focus and making sure that the feedback is representative for both patients and providers. You know, there's a number of different activities that we are thinking that this group could help inform and based on whatever those activities may be, we may need to add a few additional members with specific expertise to the task force. And if that's the case, you know we'll do that and we'll let you all know.

So this will likely be more of an ongoing task force than some of the others where they have a very short start and end time, focused on one item; whereas this group will focus on many. The next...or the first item that we'll have you all focus on is going to be related to the Blue Button website which we're going to talk about a little bit more, and we actually need to update this slide to reflect that. And then the second item will be a tool that ONC is working on that we'll give you more information about soon.

So, if we go to the next slide. So actually I'm going to turn it over to Lisa, I believe, who is going to kick us all off. So the first item, as I mentioned, that this group will be giving feedback on is the Blue Button Connector website. I think the consumer team is just going to give a little bit more background about who they are what the website is hoping to achieve and how you all can help inform it. So, Lisa, to you.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Great, thank you Michelle. Can you hear me okay?

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

We can.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Wonderful, thank you. So excellent level-setting; thanks for that. We just wanted to, before we dive in more into the content, we wanted to provide this group with some insight into the consumer team, where we're coming from and, you know the next steps that we see in our immediate future and how to pull you all in. So to start, my name is Lisa-Nicole Sarnowski. I am within the Office of Programs & Engagement at ONC and the consumer team is a very wonderful part of that office. And so I'll be filling in for Lana while she's out; she will be here moving forward, but you'll hear myself, Liz and Margo; we're

sort of tag-teaming this as we go to make sure that we're able to give you as much information as possible.

So we wanted to kind of start off with the overall vision of HHS, which we all know to a certain degree. The...we're really trying to shift the conversation from more of a what Brian kind of classified, and I'm paraphrasing, but more of a siloed approach, which I think can sometimes happen where we talk to patients in one room and providers in another room and developers in another room and then we say, all get together and talk amongst yourselves. And I know the team has been doing a great job in really getting that ball rolling, but we want this task force to continue that work.

And so the goal is to shift more towards the value-based payment and the delivery system reform. On this slide you see the HHS goals for the Medicare fee-for-service shift in this area, as well as some of our next steps. But I think the next slide does a good job in helping this team identify where we can hone in, and that really is in the second focus area, the delivery...I'm sorry, the care delivery area.

And the three bullets here you see are encouraging integration and coordination of the clinical care services. And, you know we talk a lot about patient being part of the care team; that certainly makes sense to fit there. There's improving population health and then, of course, promoting patient engagement through shared decision making. And so a lot of the work that we'll be doing both here at ONC, but again as this task force is really trying to feed into these larger delivery system reform efforts. Next slide, please.

This slide we wanted to share with you, thanks to feedback from Donna actually. And, you know the thought behind this slide was we know providers care about and engage patients on a daily basis. They work tremendously hard to do so and so not only do they have it as kind of part of their day-to-day work, but there's also regulatory reasons why patient engagement is important, one of which is Meaningful Use. And so on this slide we just lay out with Stage 2 and 3 Meaningful Use, what the sort of requirements are that providers are held to should they participate in the program. And a lot of that has to do with patient education, know resources that are really specific to the patient.

The VDT and secure messaging and you know, it changes from Stage 2 to Stage 3, as you see here, but the underpinnings are really both technology and person-centered. And we wanted to give credence to that, keeping in mind that of all the things that the providers need to work on in working with the patient to make sure that they have the best care possible, these are other things and other considerations that if we can build tools that help make these processes easier for them, we would like to do that.

We also, just a side note, have a hyperlink at the bottom of this slide; all of the language here was pulled directly from the Meaningful Use Stage 3 Final Rule and other CMS materials. They do a great job of providing educational resources, so I would encourage those who have not had a chance to take a look at their website, to do so. Next slide, please.

Excellent. And so with that, I'm actually going to turn it over to Liz, on my team, to provide more of a shift from the provider considerations into more of the data that we have behind why this is important, how far have we come and, you know starting to set us up for the conversation of where we should be going. So Liz, please take it away.

Elizabeth Heintzman, MPP - Health Insurance Specialist – Centers for Medicare & Medicaid Services

Thanks Lisa. This is Liz Heintzman and I am part of the consumer team here at ONC and as Lisa mentioned, I'd like to now talk about why it's important for consumers to access healthcare data and I want to show some infographs and statistics. So due to HITECH and other policy, culture and technology changes, more patients have access to their health information online. As you can see here, in 2014 six out of 10 hospitals provided their patients with the capability to view, download and transmit their health information, which is a significant increase from 2013. To the next slide.

And additionally, more hospitals are adopting patient engagement capabilities and this includes requests to amend healthcare records, request to refill prescriptions, scheduling appointments and paying bills online, as well as to...patient data and sending and receiving secure messages between patient and providers. And as you can see from the bar graph, the percentage of hospitals implementing these capabilities has grown with each year. Next slide.

And so patients do value their online access to health records. An ONC survey indicated that seven out of 10 individuals valued the online access to the healthcare data. And we also have found that age is not a factor and actually 67% of adults age 65 and older said that accessing the medical information online is important to them. And then next slide.

So not only is it important for consumers to view their healthcare records online, what's also important was how they engage with the health information. Um 55% of individuals who are offered access viewed their records within the last year and six in 10 individuals claimed that viewing the records improved the desire to do something about their health. And next slide.

So individuals are also using their health information to actually manage their healthcare data. As you can see here, on this infographic, more than half, about 67% use health information to monitor their health while over 30% actually shared their healthcare records with someone else and downloaded it. And also people kind of moving to Apps and using that as well to access and use the healthcare information. And next slide, please.

So not only is gained access to healthcare information important as I mentioned, but also how information is used is just as critical. Electronic healthcare information can lead to better healthcare. Statistics show that it improves communication with healthcare professionals, allowing for corrections to errors in medical records, increases knowledge of health and motivates individuals to take action with their own health and their healthcare. And next slide.

And actually, so physicians do support patient engagement. As you can see here, it is high percentages of number of physicians that believe that patients should be able to update their information, such as demographics, family history and medications in their healthcare records. And moving to the next slide.

Although we have come a long way in providing consumers access to their healthcare information, there are still challenges. And one of them are gaps in consumers information with one in three individuals experiencing a gap in how their information is being exchanged; and whether that's through having to redo a medical test or procedure or providing medical information again because their chart was lost and not found. And I'm going to turn over to my colleague, Margeaux.

Margeaux Akazawa, MPH – Presidential Management Fellow, Office of eConsumer Health, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Great, thanks, Liz and thank you Lisa. This is Margeaux Akazawa; I'm with the Consumer eHealth team here at ONC. If you can go to the next slide...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Margeaux, before I...well, go ahead and I'll stop it after your portion; go ahead.

Margeaux Akazawa, MPH – Presidential Management Fellow, Office of eConsumer Health, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Certainly, okay. Great. Yeah, so I think Liz outlined what the challenge is; I think an additional challenge that we have identified is that consumers obviously don't go through just one encounter with the medical system. As you can see here, a Medicaid patient visits a number of primary care physicians, specialists and different practices throughout their...throughout a given year. And we realize that this isn't just limited to Medicare patients, that this is actually an experience that many consumers go through when they aren't even...aren't on Medicare and so this means multiple patient portals, lots of coordination and all of that is on the consumer's shoulders.

And so while this is a major challenge for consumers, it's also a potential opportunity as individuals serve as the hub for their information exchange. And consumers are truly the center and understand the consumer journey through which...and the...in which they go through for their healthcare can help us identify ways to better engage and empower these individuals in their care and the...or the care of their loved ones. So if we can go to the next slide, please.

So just as there's challenges for consumers, we also realize that there are challenges to patient engagement for providers as well. And so ONC conducted research on providers this past year. Based on the feedback that Meaningful Use requirements for patient access were unfair so we spoke to 19 people from various positions in the hospital systems and care settings and this is what we heard; so, if you go to the next slide.

So positive news, overall providers and hospitals believe that electronic health records and patient access to them will ultimately improve patient care and outcomes; in fact, the providers, office staff and hospitals reported seeing improvement like reduced time and cost to their work since moving to EMRs. However, physicians and hospital personnel desperately wanted to talk about the larger systemic issues that prevent them from being able to use patient data in a meaningful way, as they would like. Can go to the next slide?

So what were some of those barriers? The challenges that informants identified were...fit into three sort of buckets; those were interoperability and information flow, second was rules and regulations and third was patient awareness. If we go to the next slide.

First looking at interoperability and info flow; this is where we got most of our comments from our informants, and some of those barriers that they listed out in this sort of category included things such as that EMR systems don't work well together causing fragmentation and duplication. Every practice and hospital has different EMR systems that don't communicate with each other. Patients have too many portals. Doctors have system overload and paper keeps getting introduced into the system either through FAX or otherwise. A lack of unique patient identifier results in duplicate information in the

system. And also it's the cost of EMRs and connections to other system is carried out by the PCPs and outstrips the incentives.

If we go to the next slide, going into our bucket of rules and regulations, some of the barriers that providers whom we interviewed mentioned here was that Meaningful Use requirements meant that doctors and hospitals create new workflows simply to be in compliance. Time to become compliant isn't always sufficient and attestation periods are too long.

Also regulation changes causes what they call chaos and more money; and also that regulations aren't on scale. If you are a small practice but yet have to fulfill the regulations in order to get any sort of incentive payment, they felt that that was also difficult for them to achieve. And then finally some hospitals and institutions interface with organizations that aren't required to participate in Meaningful Use, and their burden was higher and sometimes unobtainable.

And then moving to our final barrier bucket on the next slide on patient awareness; and so this was identified as a barrier, but again much to...to a lesser degree than the previous two. And that was, some of the barriers that they identified in this section included that practices and hospitals felt that educating patients about access to their health information falls squarely on their shoulders. And practices spend time and money getting patients signed up for portal access, but it achievable...but they feel that this is achievable compared to some of the larger interoperability and regulation barriers that they are facing.

And so as one doctor noted, and these pictures on the bottom just sort of indicate...show what one provider's office did to get patients to sign up for their portal. And as one doctor noted, we're doing it, but the acceptance rate of it has been minimal and we have to really promote it.

So we wished just to share these findings with you guys for this group on some of the challenges that most providers were facing. So with this sort of level-setting section, I wanted to turn it back over to Lisa to give a little bit of an overview of what we at the Consumer eHealth Office do at ONC.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

It's...yeah, sure.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Can I...this is Donna Cryer, can I interrupt for a moment.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Absolutely.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Umm, because this has been a fantastically rich bolus of information, and I really thank you all for putting it together, but I say frequently that my healthcare needs are complex so I try to keep the rest of things very simple. So just to give some context and framework for the task force members who are just looking at this information although not for the first time since they're so familiar with the landscape, but at least how it's been presented; I just wanted to simplify our charge.

Although we will be asked to make specific recommendations on two products of interest to ONC and part of the larger ONC HIT plan, it really boils down to physicians, clinicians, hospitals, health systems in trying to meet Meaningful Use and in trying to overall advance the way that they engage patients in using...in accessing and using their health data have experienced challenges. And so the same group that has the challenges clearly could not...if they could have figured it out for themselves, they would have done so and we would, you know, we wouldn't have the need, we'd all be getting a, you know enjoying a nice spring day or walking our dogs or something like that.

So we've assembled this group, specifically diverse, so that the patients, caregivers, members we can give our feedback on recommendations as to how to engage us and our colleagues, our peers more actively in data and exchange of information with health systems. And we specifically wanted the clinicians and those from health systems and from payers and others on the panel to help make sure, give us guardrails if you will, and help make sure that what we're suggesting from the patient and caregiver perspective makes sense from a practice workflow issue.

So that at the end of this task force, we will have delivered recommendations to the HIT Policy Committee that really does solve the problems, or at least advances in a way and is helpful to healthcare systems and practices. And we specifically wanted to make sure that everyone from, you know small practices, pediatrics facilities as well as those that serve adults and seniors would find help in our work that we would be able to provide recommendations to move them further towards successfully engaging patients with their data; that's the bottom line.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

This is John Derr, I have a question.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Yes.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

You've talked a lot about Meaningful Use in that...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

...and as I stated before, I represent long-term post-acute care and I've had this problem since I've been on the Standards Committee of whether we do or do not fall within the scope of the study and just pointing out that 40% of the people discharged are going through transitions of care from a hospital go to either a skilled nursing facility or nursing center or a homecare agency.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

And where we see them for 25 days in SNF on an average or in a home care, 60 days, where a lot of patient engagement and consumer education can be done. As an example, in the SNFs, each one of them have a home place where they teach people how to operate when they do go home, because we do want to transfer them to their homes.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

So, are we included in this, since I see Meaningful Use a lot and PCPs and hospitals, health care systems, but no mention of long-term post-acute care? Sorry for my windmill, but that's why I ask.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

No, no, no, no, no, that's exactly why you're here, to point out those gaps. So...

Brian Ahier – Director of Standards and Government Affairs – Medicity

So this is Brian, if I could just add on to what John said, because...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Please.

Brian Ahier – Director of Standards and Government Affairs – Medicity

...first off, I agree with him completely. I think that, you know, the post-acute care settings that have not been a part of the stimulus funding from HITECH for the adoption of digital health tools have sort of been left out in the cold, and I...that's a little bit tragic...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

Brian Ahier – Director of Standards and Government Affairs – Medicity

...because they're, you know, that's a very important part of the healthcare continuum and I know that CMS and ONC recognize that, but, you know you can't boil the ocean. So taking steps towards getting all of us connected and really having a learning healthcare system, you know...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

Brian Ahier – Director of Standards and Government Affairs – Medicity

...we're on a journey and we haven't reached the end of that journey, if we ever do. You know, and from personal experience I can say this is what drilled me into healthcare, I used to just be a computer geek, but you know, then my mother had Alzheimer's, early onset Alzheimer's, she was only 52 and over the course of four years, it was very aggressive, she was in and out of the hospital, she would fall, go to the hospital, she'd have problems, she'd go to the hospital. She would be discharged from the hospital to a

skilled nursing facility and then from the skilled nursing facility go home and be on home health and then, you know, maybe get back in to see her doctor before she was readmitted to the hospital again.

And it was a revolving door, a spiraling down of less...of decline of health and decline of quality of life. And there was very little care coordination between all these disparate systems. Well now this was back in the '90s and so, you know, we didn't have all the great tools that we have today. I mean in some cases we haven't really made that much progress, where we're faxing a lot of information, where we're not communicating...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

Brian Ahier – Director of Standards and Government Affairs – Medicity

...with patients and their caregivers. One thing I want to point out though, as we talk about Meaningful Use, while the EHR Incentive Program is still fully in force...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

Brian Ahier – Director of Standards and Government Affairs – Medicity

...under the HITECH Act and the regulatory regime that CMS and ONC have for inpatient facilities and hospitals, physicians are being very quickly, you know beginning January of next year, going to start gathering data to report under a new system, the Merit Incentive Payment System or alternative payment models under MACRA; the law passed last year.

Now I also want to point out that the view online, download, transmit, the secure messaging, the care coordination through patient engagement; those particular objectives of the Stage 3 Meaningful Use Program have been adapted into the Merit Incentive Payment System and so they will be a really critical and key component of, you know through payment mechanisms from CMS for clinicians to succeed. While the clinicians in year 1 are doctors and then mid-level providers like nurse practitioners, PAs, nurse anesthetists and so forth, they talk about in the rule that...in the proposed rule that in year 3, they have authority under the law to expand the scope of that and include other providers such as those that John was talking about like occupational therapists, physical therapists, folks who work in some of these outpatient settings.

So, I'm sorry for a long-winded sort of insertion there, but yeah, I think that that's a r...John, that's a really good call-out and I think it's a really important thing for us to keep in mind that we're not just talking about hospitals and we're not just talking about doctor's offices, but we're really talking about the entire healthcare continuum.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Excellent, I think and John that was...Brian, that was a great lead in to my...I just had sort of a statement and then a simple question before allowing to proceed with the agenda. So my question...

Kevin Fowler – Consultant – Kidney Health Initiative

Hey, Donna...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Yes, go ahead.

Kevin Fowler – Consultant – Kidney Health Initiative

...yeah, this is Kevin, I guess I'm just trying to think about, in terms of what the role is, is that I guess at what point can the patient or consumer part comment upon what's been presented here? So I don't want to take us off track...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

No, no, that was my question. My question was to the group, with what you just...the slides we went through, does...how you feel about that, the information. And did it reflect the reality, the world as you understand it? Is there different information, new information, ways of presenting the information or push-back even on the information that was presented? So I just wanted to give you all the opportunity for conversation and engagement before we sort of keep plowing through.

Kevin Fowler – Consultant – Kidney Health Initiative

Yeah, and I appreciate that, Donna. From my perspective is that, so let me preface it at, you know like yourself very engaged in my healthcare. I would sign up for, you know the portals and records, but I've never used on, never used one in my life. And I can share with you is that I think what these doctors are mentioning that they feel like this education, and it really is not an education like you're just told to sign up for this.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

Kevin Fowler – Consultant – Kidney Health Initiative

So what I see as being absent, you know looking at what the reality is and the level is that really the value proposition of what the portal or electronic health records will offer has never really been defined by the healthcare center. And I go to a top healthcare center and I'm doing tests that could easily be done on the...with my record and online, except the healthcare system hasn't embraced it. So there's...the task has been done, the checkmark's been done, but how then that translates into improvement in the workflow and everything, is not even close being happening.

And again, that's been...and then I would just add another thing to this is that if a...if I fall in the category of being a very engaged individual, what about the general population where we have no...we have a very low health literacy rate in the United States. So I think that's a basic...so the...I guess to kind of summarize my comments is that, the value proposition has never been fully defined, nor has it been communicated. And then the looking at the, you know making this...pulling through on both sides, you need healthcare leadership to embrace it and then you need to have patients begin to understand why this is good for them. But I can just tell you; to me it's all been a fantasy in terms of what has been...the value it could offer versus what's happening on the ground level.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

So how do you...

George Mathew, MD, MBA, FACP, CMQ – Medical Director, Quality Measures & Analytics – ActiveHealth Management/Aetna

This is...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie...and I'd like to add a couple of things to Kevin's comments and I will...there was a recent study published at the...2000 patients...and that on using health Apps and actually they found that people had a strong desire to use them and the biggest breakdown on the perceptions of whether they were useful were people were actually using them and the people that weren't. People that weren't thought that they were pretty useless; the people that were, thought they were okay and getting better.

I do think there is a use and non-use perception, but also the...we are quite, I think, arrogant as an industry to think that if we build it, people will come and that that value is determined by what we want people to do. Generally value is created or value's determined by what customers want the services to be provided to them. And so we...

Kevin Fowler – Consultant – Kidney Health Initiative

Exactly.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

...still somewhat...we have incongruence between the usability and value. And then thirdly, I often talk about Wells Fargo because I have many different types of uses with online banking, but when I'm doing well financially or I'm putting appropriate things in my savings account, I don't look at my savings account; it doesn't mean it that doesn't have value, it just means I don't need it that bad. So we have a value continuum we have not defined well in healthcare and not done it by what the patient wants; so we have a ways to go.

However, we do have really great signs of improvement in just those last five years that the previous slides have shown, where I can remember thinking all of us were whackos...when we would talk about patient engagement and access to records and folks would say, why would you do that; they're just going to call us more and it's going to be difficult. And none of those myths have proven so I'm encouraged by this gap that we've been shown and hope we can help to...

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

Mm-hmm...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Can we go back to the slide on umm, that was bifurcated by frequency of use, that's in the deck, because I think it speaks to this value continuum and the value proposition and the ROI and it was the one place where I felt that we were really, well, there were actually a few places, but that was one place that I really thought was helping us sort of get down to that level of detail, which I think is something that we ultimately need to...

John F. Derr, RPH – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

While you do that, can I...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

...perhaps better articulate to the health systems that we're attempting to help do this effort. And yes, go ahead with the...who, and please announce your name first.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

This is John, its John. Have we defined whether we're involved in engagement or education, because those are two different things and as we go through, and even when you come up with that slide, engagement I think to many people think is just a, we sent them something, so they're engaged. I know when I'm over at the hospital they'll give me my...all my blood tests for the last week or so and so I'm engaged, right, they're check-off list. And...but it's the education of somebody to say, okay, what does this mean and I sit and talk with my doctor for long periods of time, because I'm healthcare so I can do that, and really get a lot out of the conversation. So I just...the point was, do we define this as an engagement and what is an engagement? Or do we...or is education part of engagement?

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

And then, I think...I have one other windmill, I'll just throw it out. I use spectrum of care because it's what we're in, we're...it's a spectrum of different cares continuum. When I was at AHCA, AARP did a study of us old guys and we found out we didn't like continuum because it had a start and a finish and we didn't like the finish.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

So, spectrum was a better word for it and if we really focus on the person and their spectrum of care and how they do in longitudinal care, which is the aggregation of all medical elements, getting trending and getting alerts and all that, we'll start to get them engaged because they can see things in a longitudinal manner rather than just a static, episodic manner. Sorry.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

So I would think, and feel free ONC staff to contradict me if I'm going...if I'm answering incorrectly, but I would like to go towards engagement; I believe that's our charge and that's why I asked for this one slide, I think there are others that also go to this point, but I'd anticipated a question I was asking, so thank you for the brilliance of the ONC staff. It shows the difference between someone who accesses their records just once versus some who accesses three or more times a year. So, you know it shows that the ability to communicate with a doctor or to desire to do something to my health or the ability to just share the information; so taking actions and making decisions is increasing with the number of times that they're accessing their information online.

And if I were to diagnose some of the problems that I've personally seen and certainly read across different literature, umm, different systems, I don't think there's enough of a differentiation of patients

that sort of draw across the various analogies that have been used, of those at different points in their life cycle or their spectrum or at different stages in their continuum of care, certainly those with more frequent visits or more complex needs for which the ROI of looking at their information and of sharing it is more clear versus those who are healthy or whether it's their finances or their health that is in good shape and so the ROI is not, you know, there not as high stakes for them.

And that's not often differentiated in health system effort and I think that perhaps, I'll state at this early stage, I'll just state it as a perhaps, perhaps that is one of the areas we would draw attention to in our recommendations of efforts to healthcare systems to better differentiate in their materials or outreach or engagement efforts, however we're going to define them, to recognize this difference that's represented on this slide, and some others, as we move forward. With that I want to...

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

This is John again, just...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Yes.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

...just to point out if the cost of healthcare, Medicaid...Medicare especially, 46% of the Medicare costs go to people, persons who have six or more chronic care conditions...and we can't go to a doctor three times a year, I mean, that's the only way...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

I know, I go three times a month to various doctors, so I getcha, umm and I think that's what this slide, you know so, you know ON, Michelle and folks, if you can show that Medicare slide that you put together so well, that infographic that I think demonstrated that point of view...that information with...

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

And I do want to say...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

...the number of specialists in care? Go ahead and then we're going to turn it back over to the staff. Yes.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

I do want to say that ONC does a great job; I think Brian said that, in recognizing the whole spectrum of care and not just what's in Meaningful Use. So, when I bring up certain things and gaps, it's not because they haven't tried, it's just because the legislation made the decision to leave out the whole spectrum of care and just concentrate on hospitals and doctors.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Great. The Medicare...this is great, I was also thinking about this one, but it's the Medicare slide with the six specialists and the four portals and the...that one, that was the slide that I was asking for.

W

The one with the patient in the middle?

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Yeah, with the patient in the middle, yes...and we'll...

Susan Hull, MSN, RN – Chief Nursing Informatics Officer – Cincinnati Children's Hospital Medical Center

Yeah, this is Susie Hull, I just wanted to...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

...yeah that one, yes.

Susan Hull, MSN, RN – Chief Nursing Informatics Officer – Cincinnati Children's Hospital Medical Center

...Susie Hull I just wanted to offer a brief comment. I think that there's some tremendous models that many of the members of this group have been building over the years. I think of the tremendous work that Leslie Kelly Hall and the NeHC Advisory Group on Consumer eHealth did on patient engagement and sort of setting the stage for progressive levels of patient engagement and defining that with a framework.

I also kind of fast forward to the great work the ONC has done on the learning health system and the roadmap for interoperability. And I have participated in giving quite a bit of feedback to that document in particular and think that the language is really pretty exquisite in the way that we talk about person at the center care. And so I think if we look at engagement, there are existing definitions that we could draw on.

In my own organization in Cincinnati we're beginning to advance a notion and potentially a technology roadmap around co-production of health services...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

Susan Hull, MSN, RN – Chief Nursing Informatics Officer – Cincinnati Children's Hospital Medical Center

...aligned with some of the work IHI and others are doing. But thinking about that we really co-produce health and care or caring with those we serve so, the function of the movement of health data, the access to the health data, the use of health data for shared decision making really is in service to, you know a number of things including co-production, including learning health system, and so I think anchoring our definition would be really helpful, but building on the strength of recent historical work that's been done, and then really looking at these barriers, umm, whether they be infrastructure, cultural, other things that we need to move the dial on in terms of growing adoption and spread of this work.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Absolutely. I think that's very well said and I love the term co-production. I simply wanted to take that pause within the meeting, because we do have such a brain trust here it would be a shame if I didn't

make sure that we heard from you. But, Lisa, let me let you proceed with a description of the work of the Office of Consume eHealth.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

And hey Donna, this is Patty; just one quick statement here...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Sure.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

...and I think you started to allude to it when you first started was that we wanted to simplify this, you know the work which I think somebody else said something, maybe John it was you, that we can't boil the ocean or...and so from my understanding, the task in front of us is to provide input for some of the tools that ONC is, you know working on. And so, you know, we've got so many people with such diverse and wonderful understanding, I'm, you know I'm thinking that...I'm going to plant a seed here, you know when they say give us input, what exactly is input?

You know, are we going to create some kind of a checklist, and it takes me back to when, you know you do requirements development for a system should, you know. A good consumer focused system should include and address the following, you know, and then we create some kind of a list as we evaluate what they're putting in front of us. So, I'm just planting that seed, you know, trying to keep it simple and, you know so that we provide to ONC exactly what they're looking for. So, I'll pass it back to ONC; thanks.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Thank you; this is Lisa-Nicole; can you hear me?

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Yeah.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

Yup.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Well first of all, let me just say thank you to Patty and to Donna; that was an excellent conversation and that's exactly where we wanted to go with this, so, I think that we're going to work together just fine. And I also learned a couple of new terms that I really like; I like spectrum a lot, I like co-producing. I'm just going to briefly go through the sort of background of the consumer engagement team and it really gets to the earlier points which is, yes, we talk about Meaningful Use a lot, you know for historical purposes and it's very important and to Brian's point, I believe, it is a significant part of our future under the Medicare and CHIP Reauthorization Act and other things.

That said, the Office of Programs, specifically the Office of Consumers have always really tried to focus on the broader patient population and yes, you can't boil the ocean, but we do recognize that the stream of consciousness exists in healthcare for a reason. We can start off talking about an acute visit and then quickly talk about, umm, coordinating with eight different levels of care and it, you know, it's just the nature of the work that we do. And so what we try to do is ensure that the consumer voice is heard at every step in that process.

And so you see on here that our mission is to really empower the consum...the patients and their families to use health IT to manage their health and partner, and I want to emphasize that word, be a partner in their care. The providers and everyone on the phone knows that a lot of the healthcare that really affects the patient's health happens well outside of the provider visit and so what can we do to help patients really move their own care forward? Because, you know, they're the most important person in that conversation. Next slide, please.

So the Consumer eHealth Strategy, I'm just going to talk about this pretty quickly, but you see the four pillars are access, contribute, share/use and culture change. It's cyclical, one affects the other and it is a continuum. And I also want to point out, too that the circle demonstrates, it's not binary. I think sometimes, early on in conversation, access and sometimes even interoperability way back when folks kind of thought, oh, I'll just connect it and it will work; not always the case.

Access is no different, it's not that you either have access to your record or you don't, we're finding there's a lot of steps sometimes that need to be taken. And so what we want to do is really increase individual's access to their own health information. It needs to be...the work that this group does, needs to, you know it could be an incremental process, but we'll just need to identify steps to get us to where we want to go.

Contribute, of course we also we want the patient to be able to be empowered to contribute important information about themselves into their record. Sharing and using of course will increase the use. And then culture change, this is really part of the shift towards person-centered health and person-centered care. Next slide, please.

And, you know the...so you'll...there's a lot going on here; it's a beautiful slide. It really outlines the work that we have done, but you'll notice that this is kind of living proof that we really believe that individuals are central to our strategy to empower them with the information and technology that they need to achieve better health and get better care. So we have the Blue Button Pledge which has support from over 650 organizations. We have a portfolio of recommended technical standards and regulations supporting patient access.

We are achieving an enthusiastic following as those on the call are definitely part of, of supporters and we have different engagements and meetings and health IT summits. And then, you know perhaps most important for this team is we're developing tools and resources for consumers, caregivers and providers to use, and we're really trying to do our best to not just develop it, but roll it out nationally as much as we can. And some of it might be repurposing and updating materials that already exist, whether it's through ONC or another organization and really just making sure that the information gets to the consumer and the provider where and when that they need it.

So here I believe I am going to turn it over to Margeaux to talk about more tangibly what our next steps are from the consumer team side. But we will also, I'd like to continue the conversation on you know, what this group sees as their charge. What they want to get out of it. I have been making a list of people who have been talking, but I want to be sure that we walk away with at least a list of things we could do and then from there we can you know, work to narrow the scope as appropriate. Margeaux? And next slide, please.

Margeaux Akazawa, MPH – Presidential Management Fellow, Office of eConsumer Health, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Great, thanks Lisa. So looking ahead, here are just some things we wanted to update the group on, on things that are already ONC-related, consumer focused products or initiatives that are already underway or coming up that we wanted to flag for the group.

One of those is the 2016 ONC Annual Meeting that is coming very soon. And one of the days of that meeting is going to be a consumer focus day; that will be on June 2. The meeting itself is free, it's a three day meeting you can go to this link or visit healthit.gov to register for that meeting and we would love for all of you to attend and to be there. And also...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Hi, this is Leslie; I just want to interrupt, and I think maybe what we could do is communicate and see who is going to be there and maybe all have coffee or something.

Margeaux Akazawa, MPH – Presidential Management Fellow, Office of eConsumer Health, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

A great idea.

W

I think that's great; I'll be there on the second.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

I will, too; this is Les.

W

Good, maybe we can have, at lunch, once I look at the agenda of the day, maybe we can figure out how to perhaps at least if not say hi or share coffee or lunch together; we'll maybe all look through the agenda for that day and suggest a time back to the group.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Perfect.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Great, and just so this team knows, our own Donna is going to be the keynote, helping us open it up and provide great insight from her experience, not just as a patient and a patient advocate, but also as longtime team member who has worked with us for the last five plus years; so, we're really looking forward to it.

Margeaux Akazawa, MPH – Presidential Management Fellow, Office of eConsumer Health, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

And also just to flag for the group, registration for the meeting does close this week, on May 19, so please be sure to go ahead and sign up before then. Another thing that we have under way is that we do have two challenges in partnership with another office here at ONC, the Office of Standards and Technology that were launched.

The first one is the Consumer Health Data Aggregator Challenge, which is to spur development of third party consumer-facing applications that allow aggregate consumers data into one place under their control. And the link here will send you to the page of that challenge to learn more about it.

And then the second one is kind of a partner to that challenge and that one is our Move Health Data Forward Challenge. And that one is encouraging development of API solutions to allow people to securely authorize the movement of their health data to destinations that they choose. So again the first one is aggregating it together and then the second one is moving it to where you would like it to go.

And then kind of going more into the future, again we presented you guys to the provider research that we have done and ONC also hopes to be doing some consumer research as well to supplement those provider research findings that we had. We are in development of consumer and provider tools and resources, one of which that we'll be asking this task force to take a look at in following weeks. And then finally we're trying to advance the Blue Button Initiative, and that's also something that we'll be asking the task force for their thoughts and opinions on as we move forward. So next slide.

So finally we'll just close with the proposed work plan for the coming weeks for this task force. And just to echo Lisa's comments is that we are...again we would love to make sure that this is really falling into where all of you feel like the task force should be going. So, the next meeting on May 26, we'll be discussing a little bit more onto the Blue Button Initiative. And then the following meeting after that, on June 13, we'll be discussing feedback on the Blue Button Initiative and then introduce one of the ONC tools that we would like for your comments on. And then June 23 we'll have a committee meeting to share the feedback on that.

I want to turn it back over to Donna and people to comment on this work plan and also any other comments on the previous slide as well.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Excellent; this is Donna. I just wanted to underscore Patty's point about being very specific instructions from you all in terms of what you would like the deliverables from this task force to be and the form and format of those deliverables so that...because we have very expansive thinkers and we all have lots of things that we would like to do to improve the entire spectrum of health. But we want to make sure that we are giving you the exact deliverable that you are going to be requesting; so as specific and as, you know bulleted and granular and straightforward as you can be about what that deliver...what those deliverables are and the form and format that you'd like to have those in, I would certainly be helped by, and I think the other members of the group would be as well.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

This is John Derr again; would you please send out an e-mail list of this group and whoever else you want to include so we have sort of a group e-mail we can mail comments to?

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Yes, I think that should be done.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

Thanks.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

And feel free to, you know if there are any...feel free to e-mail me at any time between meetings with any comments, questions or concerns and I will certainly work those out with the ONC team here that we have. One thing that, a last thing before I just open it up is to clarify some of the inclusion of Meaningful Use, and I want to thank you Brian for pointing out, you know the effect that MIPS and MACRA will have on this.

The question I had posed was what regulations and policies are the health systems that we would be making recommendations for reacting to? So I just want to...I wanted to make sure that if there were hurdles or thresholds that they were being asked to meet that we were...we understood them sufficiently enough as a task force to be able to give recommendations that would help them meet them.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Les; on Table H of the rule...proposed rule, outlines all of the member engagement, the care coordination and other areas that providers can choose from in their incentive payment program, and there are some really great themes in there that we might want to review at later meetings and/or provide some comment in support.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Mm-hmm.

Brian Ahier – Director of Standards and Government Affairs – Medicity

Yeah, this is Brian; and so, you know without getting into a long dissertation of the 962 page proposed rule, which is a dense document, but the portion of the Merit Incentive Payment System that deals with what we're talking about, they don't call it Meaningful Use anymore, they've...we have a new term now, Advancing Care Information. And that's where those regulatory regimes from the EHR Incentive Program which they've adapted towards the Merit Incentive Payment System, those are also requirements within the other track, which is the alternate payment models; which I can tell you in the commercial market, you know we're all looking at that very strongly as well on how we can, you know really succeed in value-based payments and what's the health IT infrastructure that supports moving in that direction.

And ultimately CMSs framework for alternative payment models after 2020 will include you know opportunities for commercial ACOs and other types of organizations to be participants under MACRA.

And so this isn't going away, I think it's really important and it is probably more long term, nothing that we can solve today. My initial reaction though, you know thinking about our task ahead in this workgroup is that the specific requirements for advancing care information around consumer and patient engagement and involvement are not very strong. In other words, just one patient; as long as you do this for just one patient...

Kevin Fowler – Consultant – Kidney Health Initiative

Right.

Brian Ahier – Director of Standards and Government Affairs – Medcity

...you meet the threshold. But really that's really no threshold at all; it's basically yes or no answers to some of these questions. And my hope is that the final rule will maybe take a stronger stand on the importance of having patients really be a central part of this.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

I certainly agree. So I think that, you know there...one could read the set of slides as they were presented and with just the regulatory language that you were outlining and say the threshold is low and the information could be detected as very rosy, so what's the problem? And so I see part of our role as, and there were I think the basis and foundation for this is certainly within this deck and maybe it also articulated in many of the models that were cited, showing the gaps, showing where there is still opportunity for growth, reflecting the reality as it's perceived by patients and caregivers.

And from that point, providing recommendations, Blue Button and whatever ONC tool to be determined to be revealed to us at some time future, hopefully we'll both be part of that. But I think that, you know even outside of that, if we were to be able to make recommendations for what engagement, you know truly looks like, what steps that are workable and feasible within a health system's workflow would be truly adapted; I too am not, you know have never signed into any of the eight portals that I'm supposed to. So how can we help make the reality of this better match and provide workable solutions that do result in engagement across the entire spectrum of care?

Brian Ahier – Director of Standards and Government Affairs – Medcity

Well, I'm signed into all five of my patient portals and they all have different information, so...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Yes.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

(Indiscernible)

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

And this is John...

Brian Ahier – Director of Standards and Government Affairs – Medcity

Do we have a working definition of patient engagement?

Donna R. Cryer, JD – Founder and President – Global Liver Institute

I think several have been proposed. I think perhaps part of what we put forward is curation of the definitions that exist and if there is refinement of those that this committee would suggest, I would assume that that would be well received, but as you know several have been cited so I'm not one to recreate wheels. I think we want to add unique value so if we can curate the definitions that have been...have already been refined then perhaps create some energy around adoption of one common definition and help people move towards that; I think that perhaps might be of use.

John F. Derr, RPh – President & Chief Executive Officer – JD & Associates Enterprises, Inc.; Founder – LTPAC Health IT Collaborative

This is John; I know all of the...I've got a bunch of portals, too; none of them are aggregated and I happen to be...I'm the navigator, I make sure they're all informed. Aggregation, especially with the APIs which I think Leslie talked about, you know comi...there are neat products coming on the market but none of them are aggregated and maybe we ought to revisit the EMR, which seems at times to get sort of buried in the whole thing. Anyway...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Right.

Kevin Fowler – Consultant – Kidney Health Initiative

Yeah and Donna, this is Kevin; I guess I'm trying to sort through this; there's been a lot of information, you know presented today. And maybe it might be helpful for you to kind of, you know bring us and focus in terms of, you know this whole scope of all the work being done, what we need to focus in upon and giving you feedback upon, because I...that's...I'm just trying to sort through all the information and where we can help provide the most value in this whole, large project.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Yes, so thank you that...thank you for that Kevin. I...what I hear and I share is a request to the ONC staff, and I think that they are...my impression is that you all...under a timeline and I know that as we've just evolved even the deck and the information and the work over the past few weeks, that I would, and I see the next meeting is about discuss the Blue Button Initiative. So I know that you do want to focus us on two specific tools that you haven't yet sort of outlined them for us.

But perhaps before we go into public comment if you could just spend a minute or two on, you know the version of Blue Button or the specifics around the Blue Button Connector that you will want us to work on. And at the end of this project, when we get to August what would you like to see?

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

This is Michelle; I'll start and then defer to a few other folks. I first want to clarify, you know the MACRA rule was mentioned during today's call; it is an NPRM so...and just so you all know, Kate Goodrich will be presenting and discussing it tomorrow at the Joint Committee meeting if you are interested in listening in and learning a little bit more. We encourage all of you to make public comment, but that is not the role of this group at this time. There's another task force that is focused on commenting on that rule; so I just want to make sure that that's clear.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

That's helpful.

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

This group's first focus is on the Blue Button website and then, we haven't vetted out the name of this other tool that will be introduced, but...so there really are two deliverables that we are starting to work on. The first is informing the website, and there are specific questions that the team has helped generate regarding the website. And then we think that will be a fairly quick turn-around and it's a good project to get this group working together, give us a couple of meetings to kind of gel the group and also inform the website and then we're hoping to have that feedback and present it to the committee in June.

We are working to probably change the August meeting date, just to keep that in mind. But then once we share this other tool that we've been talking about, we will then take a number of meetings to walk through that. We may share it in August, it may be later; we need to kind of work through getting some more meetings on the calendar and walking...and actually seeing when we're able to share that tool with you all; so that's what we're waiting on. Lisa or others from ONC, do you want to add anything?

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

This is Lisa; I think that...thanks Michelle; that was exactly right. And to the team's questions I think the feedback itself is really contingent on the tool that we're discussing so, for example, the Blue Button, it might be more conducive to a conversation perhaps see slides that are informational and showing what the FACA in the larger meeting because the engagement you'll have with ONC for feedback will sort of be in, you know real-time during our discussions but then taking a step back and kind of coordinating the groups comments, again in a more public forum would really help us to kind of take that charge on.

And then when it comes to this tool that is forthcoming, the one that shall not be named I guess, you know once you guys see it, I think then we can identify the best path to get feedback. It could be in document form, it could be in sort of a memo or again it could be in conversations and really specific areas and, you know bullet points on the PowerPoint deck as to considerations that we should take into account when we update it, and other resources to incorporate.

So I'm not trying to be vague but it really...we want you to get the most out of this and it'll just depend on what you think is valuable. And so that shorter term; longer term I think we have a number of different items that we could discuss, to Michelle's point, MACRA, the NPRM is in...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

Not one of them.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

...you know, exact...I started to say that and then I thought, yeah. But...

Donna R. Cryer, JD – Founder and President – Global Liver Institute

No, that's fine.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

...so, but we do have good things that we can focus on. So ONC, we will take it back as an action item to coordinate our thoughts and our notes and then circle back with you all behind the scenes.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

So what I heard, I'm just going to try to do a real recap because I know we have to open it up for public comment for...what I heard was that the purpose of today's call was to introduce each other and to do some level setting on the role of the division of Consumer eHealth and give us a common understanding from our various, because we come from various perspectives, on the current state of affairs in online access between patients and health systems. And that our actual work will be determined by the tools that will be presented to us in future meetings.

In the interim, we're asking that everyone who can register to attend perhaps, well you can attend tomorrow's HIT Policy Committee meeting, attend the ONC meeting that starts on May 31, and will have a Consumer Day on June 2. I will look forward a time to...for us to suggest a face-to-face meeting for those who are able to attend on June 2 and we will move forward from there with guidance from our ONC team. And so if you then would like to open this up to public comment or do otherwise, I will turn this back over to you all.

Lisa-Nicole Sarnowski, MHS – Senior Advisor, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

That sounds good. Patty, do you have any final comments as well?

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

Nope, I think Donna did a great job pulling it all together for us. I'm looking forward to rolling up our sleeves and starting to give you guys some good input on the tools you're developing. So, I guess let's turn it over for any public comment or questions; thanks.

Public Comment:

Lonnie Moore – Virtual Meetings Specialist – Altarum Institute

Okay. If you're listening via your computer speakers, you may dial 1-877-705-2976 and press *1 to be placed in the comment queue. If you are on the telephone and would like to make a public comment, please press *1 at this time.

Okay, it appears that we do not have any public comments at this time. Thank you all for joining today's meeting.

Donna R. Cryer, JD – Founder and President – Global Liver Institute

I think we stand in adjournment then.

Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System

Great, thank you.

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

Thank you.