



## Collaboration of the Health IT Policy and Standards Committees

*Consumer Task Force*

*Final Transcript*

*September 8, 2016*

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### Presentation

#### **Operator**

All lines are now 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 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. Patty Sengstack?

#### **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. Donna Cryer is not here. Angela Kennedy?

#### **Angela Kennedy, EdD, MBA, RHIA – Head of Department & Professor of Health information Management – Louisiana Tech University**

Hello, Michelle.

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

Hi, Angela. Brian Ahier? Carolyn Kerrigan? George Mathew?

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

Here.

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

John Derr? Oh, hi, George.

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

Hi, how you doing?

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

There is an echo.

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

That was me, John Derr.

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

Hi, John. Kevin Fowler? Leslie Kelly Hall? Mark Savage?

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

I'm present, this is Leslie and I think Mark's joining in a second.

**Mark Savage, JD – Director of Health Information & Technology Policy & Programs – National Partnership for Women & Families**

Mark has joined as well, I just joined.

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

Rather Brian Ahier, thanks.

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

Thank you. Hi, Leslie and hi, Mark. Susan Brown?

**Susan Brown – Health IT Director – Telligen**

Yes.

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

Hi, Susan.

**Susan Brown – Health IT Director – Telligen**

Hi.

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

Suzy Hull? And did we get Brian? Okay, from ONC do we have Margeaux Akazawa?

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

Yes, I am here.

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

Hi, Margeaux.

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

Hi, everyone.

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

Okay, with that I'll turn it over to you Patty.

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

Well, thank you to the small and mighty group that we have today. I think a lot of people just, you know, with the holiday on Monday just decided to go ahead and take the whole week off which is great and I'm a little jealous. So, we'll go ahead and get started. I don't think we need to...I think we've all been here enough that we don't need to do any other introductions, I don't think there's anyone new that's joined us.

So, today what we're going to do is to do an overview of just a quick summary of the discussion that we've had about the Blue Button Connector and the Patient Engagement Playbook just to make sure that what we have summarized on these slides are the points that we, as a group, want to make sure that we make to the Joint Committee meeting on September 13<sup>th</sup>. So, as I'm going through the summary slides kind of jot down if there are some things that you think were missing or we should add.

And then, I guess our partners at ONC are going to go into something new that they would like our feedback on, something called the Model Privacy Notice overview and I think they're going to give us some homework too I see and then we're going to just review the fall work plan and the calendar coming up and discuss next steps.

Okay, and then, let's see I'm on...if we can go to, let's see, sorry guys, I'm still trying to get onto the website so I'm just going to make sure I'm on the same slides that are on the other one because I just got back from driving from Richmond to DC, so the charge, I'm on slide four, so the charge as we all know is to bring us together to take a look and provide insight on some ONC and HHS projects and initiatives that have a consumer-focus, they want us to make sure that we keep the person at the center of our discussions and the tools that they're showing us and an engaging experience and feedback of both patients and providers.

So, our focus today, again, is just a quick review of what we've done and then the Task Force will be charged with providing feedback on the Model Privacy Notice and the deliverables around patient generated health data, so to come, I can't wait to hear it.

Okay, so, let's just do a quick review of the things that we talked about in the past and again make sure we're going to do the Blue Button Connector first and then the Patient Engagement Playbook. So, again, just as I go through these and as you look at these on slide six let's just make sure that these are the points we want to make at the Joint Committee meeting.

So, the Blue Button Connector, remember that was the first thing we did, we're going to kind of go back in time and what we said is that there's still a need for something like the Connector because of, you know, all the members agree it is still very challenging for consumers to get their health records online and members noted that, you know, there's kind of this issue with what's in it for me so, you know,

people don't have time, there is the incentive, you know, why should I go to it, and, you know, is that clear enough in this document or website, training and promotion of tools hinder consumers from accessing their health records so those were some of the challenges that we noted.

Overall we felt that it was really pretty easy to navigate from a usability stand-point we thought it was good. And we felt that the site primarily targeted consumers rather than other audiences like developers and I know there was a section for the developers that we thought was kind of hidden as I recall.

We also said that or we commented that the site needs to be more clear in explaining the Connector's role in assessing data and set expectations for users of the site, so, you know, once you've looked at it and once you've used it, you know, what do I do next, what expectations should I have after looking at it.

And then some members or some of us felt the Connector could serve as a resource for education and health literacy and could provide more context on why, here's the "what's in it for you" why getting your electronic health information is important. I think that's a real important message to get out there. I say this because, I'll go off on just one quick tangent here, because here at the Bon Secours Health System we've just had a month long incentive program for...we paid \$5.00 to every staff member who signed a patient up while they were in their presence in our ambulatory facilities for the month of August. So, you know, if you came in as a patient the staff member got you signed up right there for their patient portal then they got \$5.00, well, you know, they didn't get the \$5.00 then but we're giving it to them in their paycheck.

So, as a result, we just looked at the data, we found that we had something like well over 10,000 sign-ups for the month and we want to hardwire that process but the next part will be the challenge, is, okay, now we've got you signed up, you know, what's in it for the patient, you know, will they see that value. So we just need to focus on why it's important, you know, now you're getting your lab work, now you're getting your discharge summaries, now you can communicate with your physician, now you can make an appointment but it's that first step I think is also the challenge.

And lastly, members noted, our group noted that updates on the site are necessary, some of the links and the videos are outdated and I think one of them I remembered wasn't working so hopefully that's been corrected.

Okay, let me stop there. So, these are the things that we're planning to share at the Joint meeting, was there anything...is there anything else on here that you can recall that we're missing or anything that we should, or I should or Donna should explain differently? I'm asking you folks at ONC too.

Okay, wow, okay, so, then I'm going to assume that then that's what we'll present, you know, if anything comes up then certainly you can just let us know. So, let's go onto...let's do the overview of the Patient Engagement Playbook, so let me go to slide eight and so this is just overall feedback on that Patient Engagement Playbook, so go back and remember that one, that we found overall the Playbook was esthetically pleasing, easy to navigate, good usability and that we really liked the examples from the field, we thought that those were very good and I believe we asked for more of those.

And then we felt that the content was engaging, the links easy to follow, again, good usability. We liked the embedded animated graphic presentations a little more interactive and we liked that and they were appropriate to the content.

We thought it was appropriate for providers and some people even suggested that it would require only a little bit of tweaking for the patients to use and thought that this should be considered. And several of us expressed that the patients are another audience again that could benefit from using the Playbook and so again consider a patient audience in future iterations.

Also suggesting...somebody suggested that we have a PDF available that's a printable form of the Playbook that could help providers share the resource with their care team or patients. So, sometimes, you know, there's that myth of going paperless so sometimes a piece of paper really does go a long way you can just hand it to somebody they can take it with them so we thought that might be helpful.

And then in regards to the title, we thought maybe it needed a subtitle to be a little clearer because it essentially was about a patient portal but it doesn't really say that in the heading, Patient Engagement Playbook, so we thought maybe a subheading would be good.

And then lastly, some of us felt that there's a need for a more granular step-by-step guide on how to implement some of the features and functions within a patient portal, it kind of, as I recall, it assumed that the providers just, you know, had the resources and the knowledge to kind of flip a switch and turn it on and all of a sudden you could start scheduling in it and the portals nowadays have so many different features we thought that maybe kind of a guideline as to what could be implemented first that's fairly straightforward and simple, and then what do you phase in next, next, increasing in complexity for these portals as you go on your journey of implementation of your portal.

And so we thought the benefits of patient engagement needed to be clearly defined, again, to encourage providers to adopt these strategies so it's again the kind of, you know, the first Blue Button Connector was, you know, what's in it for me as a patient, this is the kind of what's in it for me as the provider using these tools so we thought that this maybe could be a little more clearly defined.

Okay, so, I'm out of breath, so, thoughts on those summary comments and our feedback? So, again, this is what we'll present to the Joint group on the 13<sup>th</sup>. Is there anything that is not there represented? Anything you want to add?

**Brian Ahier – Director of Standards & Government Affairs – Medicity**

So, this is Brian.

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

Hi, Brian.

**Brian Ahier – Director of Standards & Government Affairs – Medicity**

Well, I just think we could emphasize or maybe just somehow expand on, you know, other ways of providing this information via the web but, you know, for some people it might be difficult for them to navigate the website, I mean, I love the website, I love the tool, it's spiffy, but there's...it's difficult sometimes for people to navigate. So, there should certainly probably be a Playbook that's an actual book that they could download a PDF and then also it might be good if there were...I know that ONC is

going to be working on an infographic, but if there were images on the site that aren't so...you know it depends on what type of browser you're using and what type of operating system you have, but the images are...most of the images are within the little video, the vignettes, which I love the vignettes, but, so more images, let's get an infographic and let's certainly make it PDF and maybe another document format as well because PDF isn't always the most friendly either.

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

This is John Derr, to build on that maybe...because a lot of people use YouTube now to put all the different lessons on a YouTube. Also does ONC...how many people have accessed the Playbook since we started talking about it? It was released, what, three or four months ago?

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

Yeah, good question, I know we wanted some of that data and I don't know if you guys have it from ONC but it would be interesting to look at some of the volume. Anybody know? Maybe you're going to be presenting this to us with the...I know that you guys have some updates, should we...did others have, others on the Task Force, have any other comments before we have ONC give us updates on those two tools?

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

This is Stephen I'm on the phone to provide an update and actually will be addressing some of those, but I just want to make sure it was the right time for me to speak, I was kind of waiting to be handed the mic so to speak and I didn't want to interrupt or disrupt the current flow of conversation.

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

Okay, we were on a roll. So, are there any other...let me just ask one time, one more time from the Task Force side, anything else that we're missing or should be sure to emphasize? Okay, if not then was it...did you say it was Steven?

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

It's Stephen.

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

Stephen.

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Stephen Konya, the one...yes.

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

I was close. Okay, why don't you...so we're on slide 9 do you want to go ahead and give us some updates?

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Sure, so I don't have the slides for this, but what I can do is I've got them typed up and I'll provide it to Margeaux and the rest of the team to then forward onto you and you can disseminate to the rest of the Consumer Task Force so they can see them in writing and I believe this is being recorded as well for those who weren't able to listen in as we go over this.

So, it's been an interesting three months, we launched the Playbook on Consumer day, we got very good positive feedback, there seemed to be a good buzz around it, we did, after I think it was about a month, a month and a half after it was released and publically made available, we did do an assessment of the accessibility and what were some of the statistics of who has accessed it and I can send around that report but it might be even better if I can get that updated so you have something that's a little more longitudinal versus just the first month where, you know, there's an initial bump...we were just going to check in on it anyhow.

But it does talk about the amount of time spent in the resource, which were the most accessed parts of the Playbook so you can kind of see where there is a little higher level of engagement, no pun intended, with the Patient Engagement Playbook and in general it also has some statistics compared to other resources, but right after its initial launch it was one of the most popular and accessed resources on all of healthit.gov and also it had some of the longer amount of time spent within the resource as well as the clicks, you know, exploring various pages within the resource. So, it performed really well right off the bat from an accessibility, you know, as far as the number of hits it has received and so on.

And I think that we probably could have done even a more concerted effort on the promotional aspect of it. We've gone through traditional channels but I think we could leverage a broader network of stakeholders and associations to get the word out and promote this Playbook and get it even more popularity and awareness of it.

So, I still talk to people in various conferences who have never heard of it and so I continue to encourage people to pass it along and share it with others and if you see it on social media re-Tweet it, repost it, etcetera.

So, having said all that let me just give you a couple of updates on what we have planned for the next refresh. So, based on feedback that we received prior to launch based on feedback we received during and at the launch, based on feedback that we received from the official feedback mechanism where it says, you know, "share your feedback" through the tool itself and based on feedback from this very Consumer Task Force we went ahead and prioritized as much as we could to get done for this first update. As you remember you might recall we planned on doing a quarterly refresh to try to keep it fresh and updated and so far we're going to be on target for that. If we feel like there's not as...you know, especially after the first, you know, one or two refreshes we feel there is not as much need to update it in that next quarter then we can always postpone it until the second quarter, so if there's not a lot to do in it we can package it for a larger refresh over more time.

But some of the more significant technical changes with the usability of the site, something that I wanted to add, some of the things that we hope to do early on didn't have time for but based on feedback and other things we're planning to have done in this next refresh we plan to go live with by September 22<sup>nd</sup> and one is the integration, which is something I'm pretty excited about, the integration of a guide for using the Playbook and it will be a role-based navigation and highlights throughout the

entire resource that make it easy for the various members of a care coordinating team or someone who has some potential interaction with the patient and that could play a role in patient engagement.

It calls out those roles in three main buckets and then right in the front it says, you know, if you're a physician or if you're a member of the hospital administration type staff or if you're, you know, one of the frontline receptionist staff, etcetera, here's where basically you can see your role throughout this document and it helps to provide a little summary and context, so if any of those individuals pick it up they'll see that right off the bat and they can either read the whole Playbook in its entirety or they can skip to the parts that they think are related to them and just see those more directly. Then as they go through the same thing it does call it out at the end of each chapter and kind of summarizes those tips for providers or tips for, you know, the frontline staff, etcetera.

So, that's something that I think, you know, we'd certainly love your feedback on but I think you'll find it will add an additional navigation feature and also help clarify who exactly this Playbook has really been designed for and that it's not necessarily for a patient although it's to benefit the patient it's not necessarily for them to use as a Playbook, it will hopefully help others who have a role to play and it also reaffirms that fact that this doesn't all lie on the shoulder of the physician that it's a team-based approach and the responsibility is pretty well distributed amongst the entire team and it clearly calls that out.

Another item is that we added the ability to print the entire Playbook right from the beginning. So, this was an oversight in the first launch where if you were in a chapter you could click the print button at the top and it would print out that chapter but that was it. So, if you were in chapter one and you wanted to print that out you had to do it there, you had to go into chapter two and print that there was no place to just print the entire Playbook and we've added a print button in the beginning that says "print entire Playbook" essentially and in that case you could also save it as a PDF or any other form of document that you convert it to and that hopefully will address some of the concerns about, you know, having this be also a paper-based resource that could be shared, etcetera. So we did add that in as well and that will be a nice little simple feature to make it a little bit easier to print and share.

We're going to be updating the feedback mechanism, that's something we talked about in the past, to be more open and transparent and a collaborative tool some of you may be familiar with Disqus which is like an online commenting system for providing feedback or reactions, it will be moderated so hopefully we won't have, you know, inappropriate comments being posted on there.

But based on the initial volume of feedback and comments that we've received we feel like we should be able to manage this pretty easily and hopefully it will encourage a little bit more community collaboration on input and what should go in there and hopefully be more engaging and we have people talking more and sharing their feedback. And so it has a lot of abilities for it to be able to export all of that comment and do some analysis and filtering on the backend as well which would make it easier and that will be at the bottom of each and every chapter so somebody can just go in and type that and you can see...if you're curious if anyone in this Task Force is curious what the comments are you can go into it and check it at any time you won't have to wait for us to provide you with an update although we would continue to provide you with more of a summary update to try to make it easier for you to see the comments provided and the feedback that's coming in.

We, in response specifically to a member of, I can't remember, I think it was this Task Force there was a question about adding a Google social media sharing button so that was an easy lift we're adding that.

In the interactive graphic number three under the giving the caregiver's proxy access there was...we added a new feature to a slide tool for a parent to use, so in the past you've had to click now it's a little slicker, you'll be able to drag it and slide between the patient's view and the proxy, the caregiver's view and so that's just a little bit more of an interactive feature that hopefully some people will find is really appealing.

We've also prioritized and tried to focus on adding some additional content updates, corrections, edits, you know, some things that popped up certainly through this committee or this Task Force but also through the public feedback mechanism there are a few things that were just very minor to be considered and so on and I can go over that in a little bit more detail specifically to the ones and I have this in a chart that specifically relates to all the feedback, the source that it came from including from the Consumer Task Force and which ones we're able to address in this first launch and which ones we're going to hold off on for the next launch for various reasons but we are going to be addressing the majority of them.

And I don't want to take up too much more time on this, but the last thing I did want to say is the next steps, I'd say the next quarter to two quarters what we're really looking for is for this Task Force to review all the submitted feedback that continues to come in in concert with your own assessment and try to really focus on what would the next chapter of content be, which will be including that goes, you know, beyond the portal and that's something that, you know, right now, like you said before, the first four chapters largely talk about taking advantage and fully realizing the full potential of the patient portal as a way for engaging with your patients, but we know that there are other aspects that go beyond the portal and how do we start to draft that content and get that included, so we're looking for ideas at some point to come from this Consumer Task Force about what that next chapter of content should include or focus on.

In addition to that we're also looking for new or more current examples of best practices or what we call the "from the field" examples that are in the current four chapters as well as other candidates for myth versus reality so it's a very popular feature we heard nothing but good things about the myths versus reality feature it's only in I think chapter two, it's only listed in two places in chapter two and we'd like to do more of that especially if there is a new chapter but even in the current four chapters if there are additional use cases, best practices from the field, you know, reports, etcetera, and also candidates for myth versus realities to let us know because we want to keep that fresh, right, we want to be able to swap out an existing best practice with an even more recent best practice that maybe goes a step further than the current example that we're sharing. We don't want this to become something that's dated with, you know, 3-year-old, 4-year-old examples, we want it to be pretty fresh, the latest and greatest so to speak.

And also looking for your help in continuing to expand the promotion of the Playbook this might be an item for a future meeting to actually review and help develop and even implement a greater outreach plan, a communications and outreach plan and get this in the hands of as many people as possible and have them using it.

And then also, one of the comments that came back from this group was for us to explore the development of a consumer-facing Patient Engagement Playbook and what would that look like and we wanted to let you know that we did include in our initial request for our Fiscal Year '17 Budget we are including a set aside for some funding to develop such a Playbook it hasn't been approved yet we're still

figuring out and making sure but it's looking pretty good that we'll have some money set aside to start developing a consumer-facing Patient Engagement Playbook.

The last thing is, and we don't have this done yet, but we would like, by next spring or so to start doing what somebody else mentioned was including video testimonials with the use of personas so rather than having a, you know, graphic that's been designed where it shows, you know, a patient or here's what the nurse says or here's what the patient says from their perspective, we'd like to have an embed video that somebody that is stored on a YouTube page for the agency so that is something that's embedded within the resource and somebody can click on that and view it within the resource without having to read the resource and they can choose to share that individual video as well.

So, if you look at the HIPAA that is a very short 2-3 minute HIPAA videos we're probably talking that's something that's even shorter than that but a chance to add a little bit more of an engaging realistic element to it by live video testimonials and so that's something else that we'd like to achieve probably in two quarters or so from here but there still needs to be a lot of work to get that done.

Are there any other questions? I think it would be easiest to e-mail across the summary because there's a lot of suggested revisions from the content perspective if there's any specific ones that you're really, you know, wanting to know the status of I can answer that now or if you like we can send this matrix chart to you that summarizes all those and the status of them.

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

So, this is Patty, I think sending us the summary would be great that way we can see all the feedback that we've given you how you've incorporated it, you know, we'll hopefully see our name on there saying, you know, this was the results of feedback from the Task Force and this change is being made that will make us all feel really good.

And then the other thing, you know, you mentioned several things in the context of kind of homework and, you know, things you want to pick our brains on, so, I guess what I would ask is for, you know, you to be really concrete with us. So, if you're asking for homework from us related to...you mentioned something about, you know, what should the next chapter look like in terms of using portal technology, you talked about, you know, providing best practice scenarios that we're aware of that are happening out there, you asked us for ideas for better dissemination and outreach.

So, you know, I'm thinking that what we need is if these are being asked of us formally maybe Michelle you could help with, you know, designating this as our homework for, you know, with a deadline, you know what I'm saying, you know, instead of just saying "we'd like this from you" without a deadline let's get really concrete about it and say...

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Certainly.

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

Hey, we'd like you to bring back one best practice each by x-date. Do you know what I'm saying?

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Absolutely.

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

Or Michelle are we there yet for these particular items?

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

And actually just let me clarify too, so since I'm not the one who staffs and supports the Task Force I was asked to kind of provide an update of the...

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

Are you there or are you talking to mute?

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

I think Stephen is speaking, go ahead Stephen and then I'll...

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

Is anybody still out there?

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Sorry, I was...

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

Patty, can you not hear us?

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Can you hear me?

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

Did I lose the call?

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

I can hear you Stephen but Patty can't hear us. Operator can you pull Patty and see if you can figure that out with her?

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

Hello, hello?

**Operator**

Certainly, one moment.

**Brian Ahier – Director of Standards & Government Affairs – Medicity**

Hello, hey, Stephen could you go ahead and send me or I guess if anybody else wants it the matrix I think that would be helpful to look at especially...

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Is that Brian?

**Brian Ahier – Director of Standards & Government Affairs – Medicity**

Yeah, this is Brian, sorry.

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Yeah, no worries.

**Brian Ahier – Director of Standards & Government Affairs – Medicity**

Okay, cool.

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

So, we'll follow up with...

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

This is Leslie, I be interested too.

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

We'll follow-up with the entire group.

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Yeah.

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

And I think that we have a work plan planned for the group and we'll work with Stephen to integrate the feedback that he needs into the work plan appropriately we're not quite ready to do that yet but we just wanted to provide and update of where we are and where we're headed but to be continued basically.

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Yeah, yeah, as I understand it, you know, again, I was going to give you kind of an update of what's happened since the launch based on your feedback and then try to let you know that and then give you kind of a little bit of sense of what some of the next steps would be since I don't manage the Task Force or staff it I figured they would...because as I understand it you have "homework" in other areas as well that are...

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

Right.

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

A little bit more immediate and so I'm just trying to give you a sense that in the near future they'll be reaching out with homework assignments based on these items but I think it's helpful to start thinking that now and especially as you look at, you know, the content updates you'll see in there something to hold off for now, you know, you can think of some of those ones that maybe would fit into a fifth chapter so to speak.

And again, just to be clear, when I say, you know, new content I think the one thing that's really missing so far and we'd like to get to is that beyond the portal aspect, you know, so much of this...and this was one of the criticism early on is that like this is basically all just about the patient portal and really it's supposed to be broader than that, right, it's supposed to be patient engagement in general and not everything about getting a patient engaged in their health and taking a more active role in that, you know, revolves solely around the portal, the portal is a tool that helps achieve some of that and, you know, facilitates easier communication and awareness and so on, but there are other aspects, you know, for that as well that could happen outside of that environment.

So, it would be good to have some of that outside of the box thinking that goes beyond the portal at some point that's addressed and maybe that doesn't take place until spring or summer of next year, maybe we're not able to get to that integrated into it, I can see that taking a while to source best practices, to, you know, examples to draft up the content and then ultimately to get it designed and implemented as a new chapter, but if we don't start thinking now all of that gets delayed further, so just wanted to put that out there.

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

Hey, thanks, this is Patty I'm back, I've no idea what happened, I love technology, I just got cut off, but thank you.

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

We'll follow-up with you Patty.

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

I'll send across that summary in writing with the matrix that kind of summarizes it. It does say like the source of the original feedback and it clearly lists, in a lot of the boxes, ONC Consumer Task Force so you'll see your name right there and then it does have kind of what was recommended as a way to fix it and then kind of the status of that so whether it's going to be done by the September 22<sup>nd</sup> refresh or whether it's on hold, so to speak, for, you know, to be continued or is going to be addressed in another way. So, yeah, I'll get that to the group this afternoon and I'm sure they send it to you with, you know, other follow-up items and materials in the near future.

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

Great, thank you.

**Stephen J. Konya, III – Innovation Strategist – Office of the National Coordinator for Health Information Technology**

Thank you, everyone.

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

Okay, I think now Michelle and others from ONC were going to be transitioning over to something new that you're going to share with us correct?

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

Yeah, so we're going to introduce the Model Privacy Notice. I think we have Mike Lipinski on the line hopefully?

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Yes, I'm here, can you hear me?

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

Hi, Mike, yes. And I just want to make sure Margeaux did you want to say anything before we turned it over to Mike?

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

Ah, I...

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Well, I thought Margeaux was going to lead and...

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

I was going to, yeah.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

I'll fill in.

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

Okay.

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

So, yeah, so I'll be leading through the slides for the Model Privacy Notice but before that I did want to introduce Michael Lipinski. Mike did you want to introduce yourself to the group?

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Sure, for those who don't know me, because I don't necessarily work that close with the Consumer Groups, but I'm our Director for Division of Federal Policy and Regulatory Affairs so I'm mostly responsible for our, you know, our regulations, our certification regulation, other regulations that we issue and work with other departments on. But thanks for having me on today, I'm working jointly across ONC in multiple office projects on the Model Privacy Notice.

**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, Mike and as we go forward as I describe and introduce the Task Force's next project, which is the Model Privacy Notice, Mike will be chiming in here and there with additional information and is also on the line to answer some additional questions as well as we go through.

So, for some background on the Model Privacy Notice, so the Model Privacy Notice or MNP for short, is a voluntary openly available resource designed to help developers provide transparent notice to consumers about what happens to their data. The approach for the MNP is to provide a standardized easy to use framework to help developers clearly convey information about privacy and security of their data to users.

We see this as kind of the approach as similar to the FDA Nutrition Fact Label or the Schumer Box for Credit Card for Disclosures. So, again, this...similar to those examples this approach does not mandate specific policies instead it helps encourage transparency of key product facts that can empower individuals to make informed choices, but unlike those, in particular the FDA Nutrition Facts Label, again the MPN is voluntary.

So, ONC developed the first version of the MPN in 2011 in collaboration with the Federal Trade Commission. And in 2011 that version was really focused on personal health records or PHRs which were really the emerging technology at the time. So, if we can go to the next slide.

All right, so here we have what the 2011 MPN for PHRs looked like, so the 2011 MPN provided a standardized template that PHR companies could easily populate with their data practices and through consumer testing of this template the MPN was designed to be simple and allow individuals to really recognize a standardized notice and quickly learn and understand privacy and security policies and data

sharing practices as well as a really easy way for them to compare PHR company practices and make informed decisions.

So, as you can see here, the MPN was separated into two sections, so first was release which refers to any transmission or sharing of PHR data by the PHR company within the company as well as to external partners or third-parties and then a second section on secure, which is really around the security of the data including storage and management of that data. So, next slide.

So, now in 2016, ONC recognizes a need to modernize the MPN to make it a more useful resource for consumers and developers in a changing health IT landscape that includes new and varied product collecting digital health information such as mobile Apps and wearable devices.

So, to help us along with this process of updating the MPN ONC put out a Request for Information on March 1<sup>st</sup> of this year and sought comment on what information practices health technology developers should disclose to consumers and what language should be used to describe those practices.

We closed that public comment period on April 15<sup>th</sup> of this year and received 13 submissions with broad stakeholders representation from developer organizations representing over 5100 members, provider organizations representing over 200,000 providers and consumer organizations with representation of patient's and consumers across the country and I know that several of you on this call actually are part of some of the organizations that provided public comment during that period. And so if you are interested you can actually view all of the public comment submissions at the link provided here on this slide. If you can go to the next slide?

So, what did we ask? So, in the Federal Register Notice for the 2016...for the update of the 2016 Model Privacy Notice we asked commenters to provide feedback on the following eight areas. The first was either scope, so what types of health technology developers should be covered in an updated voluntary MPN?

The second was information type, what information types should be considered in and out of scope of the MPN?

The third was around information practices, what types of practices involving the information types should be included in the MPN?

The fourth was on sharing and storage, so what are the privacy and security issues that consumers are most concerned about or they should be concerned about when their information is being collected, stored, or shared?

The fifth one was security and encryption, what information should the MPN convey to consumers regarding specific security practices and what is the level of detail there that would be really easy for consumers to understand?

And number six was access to other device information, so what types of information an application is able to access on a consumer's smartphone or a computer, or other device should be disclosed in this MPN?

Also, the format, how should the MPN describe these practices and how should the format really be looked for sharing this information.

And then finally, information portability, so how should the MPN describe to consumers whether an application enables the consumer to download or transmit their health information?

And so from all of the 13 comments that we received during the public comment period we collected the comments on these eight areas and incorporated this feedback into draft content for the revised version of the Model Privacy Notice. But as everyone on this call I'm sure is acutely aware, privacy and security can be a very confusing and complex topic for consumers to understand so this is where all of you come in.

We would like your help and expertise as consumer and patient advocates to really provide us with consumer focused input on the draft content to ensure that the MPN is really understandable and engaging from a consumer's point-of-view and that it also addresses consumer's concerns around privacy and security of their health information.

So, with that I'm going to turn...if we can switch over actually to the Word document and I'll also take a moment before we jump into this to see if there's any...just to see if there's any questions from the group before I proceed?

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

This is Leslie and I do have a question and thank you for this work and I would like to highlight the original work done actually won award from the standard for plain language and really spent some time making sure that the information was consumer friendly and I'd like to make sure that this kind of due diligence is also done as you go forward.

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

Definitely, thank you so much Leslie, and, you know, we really...we are doing all we can to make sure that this content is really consumer friendly that it's written in plain language, that it's also really meeting the needs of consumers and so with that, you know, we are turning to all of you for your help in this as well and would love your comments and feedback and, you know, especially given your roles and expertise in patient and as patient and consumer advocates. Mike is there anything else you'd like to add to that?

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Sure, I'll just...just one point to add and I will get more into this, but, just a bit of framing, so this is...as Margeaux mentioned we received the public submission used that to inform the draft you have before you but also internal conversations and again conversations and feedback from our federal partners who participated the first go around, and so this is just another step in the work plan that we're looking, you know, here to get the consumer organization feedback and consumer member's feedback of your organizations and we'll be, you know, going through other steps through this process before we would be, you know, in a position to leave something that would be, you know, comparable to what we did last go around or that we would hope would be used. So, just to level set in terms of, you know, what you see before you isn't...you give us feedback and we're done, that approach, but we feel like part of that process is this is one of the steps.

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

So, we would have a chance to respond in writing, this is Leslie, again, back or do you want all responses verbal in the meeting?

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Well, no, I think...

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

So, we are going to be...

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Margeaux is going to go through the...

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

I'm sorry, go ahead.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Yeah, I just wanted to level set, but, yeah, I think as to the specifics, you know, we're going to get to that and she'll go through that.

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

Yeah, and so we know that this draft we would love, you know, your actual written comments so this is actually going to be what you'll be responding to for your homework is the draft in front of you that was also shared through the...before the meeting as well and we are going to be providing everyone with a week for your review of this document. So, again, if you could provide us feedback by September 15<sup>th</sup>.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Oh...

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

Also...

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Margeaux maybe there was a little bit of confusion, so in terms of the feedback we were going to hope within that weeks' time that the public, who would be listening to this being a public meeting, would be able to also provide feedback and we were hoping then that this feedback would be shared...well, we're not hoping but we would share that feedback with you and then we were hoping that you could take that feedback and inform all your comments. I think you meet again on the 27<sup>th</sup> is that correct Margeaux?

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

Yes that's correct.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

So does that...that was my impression of how we were proceeding so...

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

No, that sounds great and I think too though, you know, I know that all of you on this call also have, you know, additional thoughts and expert, you know, interest and, you know, comments, so, you know, we would love those also in writing even before we aggregate the comments that we get through the public mechanism today.

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

This is John Derr, can I ask a question? Are we going to take every PHR and the federal government is asking to look at all of that, everyone's PHR and then will collect that data for marketing, etcetera without scrubbing it with people's names? Let me...I'm trying to get the, what is this for?

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

So, this is again a transparency tool. So, this is...I guess an easier way to think about this is imagine if you look at like a nutrition label for two cans of soup the nutrition label is not telling you...it's just telling you what's inside the soup, the amount of sodium, you know, the amount of the ingredients inside of that soup it's not telling you to buy this soup or that soup, it's not telling you anything about, you know, which one is better than the other, it's really just trying to provide you with a transparent notice of what's inside that soup and you as a consumer then have more information to really base your decision on...

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

Yeah, and I...let me interrupt you.

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

Certainly.

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

I agree with that but then I'm looking at "we collect" because I want that to happen because I was with the pharmaceutical and we started to get our package inserts and all that but then I'm looking at your columns that says "we collect and use this kind of data for marketing and advertising, medical and pharmaceutical research, and reporting about it" and I don't understand...

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

Yes, so, I think...

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

John...

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

Yeah, sorry, and if I can jump in, so...and you're getting...you know you're well ahead of us because we haven't quite wanted to provide some more background on this document that you're seeing before you do your review is that here this is the "we" in this case, so whenever you see the word "we" that's referring to the company, the tech developer and you and your is the user or the consumer.

So, this is not from the...again, this is not the federal government this is...or ONC, this really would be similar to the example that we showed for the 2011 MPN where it would populate with the PHR company's information. This would populate with the developer's information meaning that all of the information, what is referred to here, is referring to what that tech, the developer or the App is, you know, doing...is how they're using the data. So, I hope that clarifies and Mike feel free to jump in if you have any additional clarification.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

No, I think that summarizes it. So, this is...what we're doing is just making this available, it's a voluntary...it still would continue to be a voluntary Model Privacy Notice that we would hope that developers and IT companies or, you know, other agencies could require use by a developer that is, you know, accesses, you know, their interface so to speak.

So, this would be...what would happen is this developer would use this and they'd explain to the...I mean, again, I'm just I think repeating what Margeaux just said and maybe that helps in terms of reinforcement, is that they would use it and that information would be provided to the consumer who is using their App say. So, I download that App to my phone I want to know what the App is doing on my phone, this is the type of information we think that you would want to know about what that App does on your phone for example.

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

I got it.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

It's just...

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

I got it.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Okay.

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

So, this is Patty, I was thinking just that, you know, maybe provide us with a few examples of some vendors that would use something like this and then provide for us when the consumer in use of that product would be presented with this information. So, do you know what I'm saying? I mean...

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

Yeah.

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

I think that's going to be part of when you purchase the App you have to do this because most people don't understand whether you're sort of stealing this and aggregating it and all that as a developer and so this is sort of telling the consumer when you buy my App I will use this with your permission to do the following things. And I would hope...I would be suggesting that the name is scrubbed and so, you know, certain that we never do any of this and submit your name to anybody or your address, or something like that. But we aggregate it in a generic sense to do these things that we will use it for. Is that right?

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

And this is also...

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Yeah, go ahead Margeaux.

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

Go ahead Mike.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

No you go.

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

And these comments are really helpful as well of, you know, letting us know too when you think consumers should be...when is the appropriate time to engage consumers with this information, again, we would like this ideally to appear before a download or purchase of an App or using a device so then that they can make that decision, you know, when they are deciding between say two health Apps that might do the same thing but might do very different things with their data or do things that they are not...one might be more in the level of comfort for them in terms of their privacy and security concerns.

So, again, we envision this as something that would appear hopefully or be accessible in a way that would be available before a use of an App but at the same time as Mike, and as we have mentioned, this is entirely voluntary and we're also really open to hearing too, from you, as to when you feel like this would be or how it can really help to engage consumers in a way that can help them make their decisions.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Right.

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

But...

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Back to Leslie's point, we're hoping that, you know, that it can be presented...and that's I think a key point that we want from you in terms of feedback is, you know, is the "plain language process" like if it is presented like this do you understand what that means as a consumer their doing with your information and if we're missing anything here too.

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

Hi, this is George...

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

This is Leslie, I'll take this internal to our organization where we have many plain language experts and provider comments with that as well.

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

Hi, this is George, I had a question.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Yes?

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

Leslie, in the example you were describing you'd want this type of language to be used in the...based on the consent that starts every App, the EULA, the End User License Agreement, is that right?

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

For Leslie's question? For Leslie, I'm not ONC staff, so my response is just, yes, I'd like to see it broadly used both any time a patient uses an App whether it's a mobile device or an App connected to HIT, the open API there's a great use case for this.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Right.

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

I'm just wondering if...since this is a voluntary process as we go through it, and obviously I want to review all the language in more detail, there may be a way to simplify it in terms of some type of certification code, if you will, where depending on the type of data sharing whether it's just used solely for the App and within the company itself or it's going to be shared with other applications, or it's going to be used, sold and exchanged that we could have, you know, either a color-coding system or some type of word designation in terms of, you know, pre-sharing versus just insular, something like that where it would be almost a quick reference for the user.

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

That's what we're supposed to...

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Right.

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

That's what we're supposed to be commenting on.

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

To understand kind of what's going on with...

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

That's our homework.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

I think...

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

And this is John...

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

I don't know if you can see it on the screen yet...

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

I've got a...

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

But those are like questions that we're asking...

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

I have to drop off.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Like that...

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

Patty, I have to drop off, sorry. This is John, I have to drop off, sorry. I'll do the homework for you by the September 15<sup>th</sup>, thanks, okay?

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

Thanks, John.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Thanks, John. The questions like those for certain circumstances are on this notice and so the other piece, just so that we're clear, we're hoping, you know, with your expertise and your resources to your members it would be twofold, one, we want your expertise feedback, I guess threefold, two, we want it informed by public comment from others on the public that are on the Task Force, so we're hoping that those comments will come in next week and then we'll share them both with you...well we'll have them as well, but they can help inform your comments that I think you guys meet again on the 27<sup>th</sup> is when we would want your expertise input that was informed by the public comment.

And I know I'm getting ahead of myself because I know I think we have a slide on this, but the other piece to that too is if you could do...we're not requesting it it's a suggestion, but we know you have certain of your organization's resources, is, you know, test with your members like a consumer testing, like if you put it in front of, you know...if Twitter is one of your members or, you know, download...Apps and they get this and they're like, you know, this works for me, this doesn't work for me, this is an answer to this question that I've always wondered or I don't understand...answering a question like "what does this mean" like that type of feedback I think would be helpful.

And again, the emphasis or point is what we're creating is a voluntary privacy notice so if you guys are familiar with like the non-covered entities report there are developers and Apps that aren't covered by HIPAA, right, so...requirements for notification, privacy notification. So, this is, you know, an attempt to fill that gap and, you know, we're not asking you to get into whether or not it should overlap or it should cover both, or should a HIPAA covered entity use this too or in place, or any...we're just asking, is this

particular one, you know, from a consumer perspective, give you the information you need to know about, you know, that product that you're going to use and what it's doing with your information.

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

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

So, I'm going to turn it back to Margeaux I think she probably wants to...it's not on my screen and I can't see the whole notice but that might be me, so there is some, you know, other issues and then she's got the work plan and so forth.

**Susan Hull, MSN, RN – Chief Nursing Informatics Officer – Cincinnati Children's Hospital Medical Center**  
This is Suzy...

**Brian Ahier – Director of Standards & Government Affairs – Medicity**

One thing before you take off, this is Brian Ahier, if you could provide us a link to where the public might go to submit comments I can help sort of get that out to the masses and help ONC publicize that they're soliciting comments.

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

Yeah, I was thinking the same thing. I think we already have a member of the Society of Participatory Medicine on the board, it would be good to get the word out because there is a lot of activated patients that I think would be very interested in this and in responding to it.

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

Yeah, this is Suzy Hull, I would also be willing to see if I could promote the solicitation but I do have one important question. We had a situation where I work, which is in a children's hospital, where we're piloting a remote patient monitoring App for a few patients and we had to look at the consent agreement for that remote patient monitoring from the outside vendor and how we would handle that in relation to our own internal privacy notices. I'm beginning to think that this could get to be a whole extended ecosystem where the patient is using multiple tools and has multiple different notices and it's quite confusing.

So, the question I have is, is this privacy notice intended to be used from the vendor community primarily and then places like ourselves who are a children's hospital or a network of hospitals we would then be able to honor that when these...with vendors that actually are adhering and are actually using this notice or would there also be implications for our own internal privacy notices and what we might need to do to change them to be more aligned with this model notice?

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Do you want to make a stab Margeaux?

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

Sure, go ahead and take a stab.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

So, I mean, you're going to be...as a provider organization you're obviously a covered entity so this isn't intended to replace those requirements so I want to be clear about that and it is geared, as you mentioned, to the developer particularly a developer that's not a covered entity that, you know, provides a consumer-facing App that, you know, doesn't fall under I guess, you know, either the business associate or so forth, but does do, you know, certain things with the information that a patient would or a consumer would want to be aware of. I don't know if that helps.

I know the line blurs here and that's fine, I think that if you want to raise that point and point...we think there is overlap with what you're already required to do or doesn't, I mean, that, I think we're open to that fact as well.

So, I don't want to...as I said earlier if it suggests precluding that I'm not precluding it but we're definitely hoping, you know, based on your expertise we can get that consumer, you know, perspective like, hey, would I do this, you know, as a consumer, does it do what I want and then we're obviously seeking, you know, some other feedback to including from developers but all perspectives are welcome.

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

And just to add a clarification as you look at this notice is that this notice does not in any way replace the more comprehensive privacy policies of tech companies. So when you, for example, when you download an App currently, you know, there is the long very detailed privacy policy that will be probably linked somewhere as you accept the term and conditions for example. Again, this notice will not replace that those will still be existing but this will be some of sort of...in a way a snapshot or provide sort of really highlight that, really key important information that consumers are concerned about and would really want to know kind of in a quick way that pulls it from that privacy policy and should they have more questions again that privacy policy is still in place, so, again, just wanted to provide that clarification for this as well.

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

Okay, so is there...so this is Patty, I just want to clarify what the ask is of our group unless was there more that you were going to go over? Where you going to go through this document a little more?

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

Yeah, I think with the time...I know that we are, you know...I want to be cognizant of time as well, but, you know, would like to just kind of walk through this document very quickly and, you know, provide everyone just sort of an overview of what the draft currently looks like and then I'll jump into sort of our ask for all of you.

But as you can see, again, this document is really pulled from a...and incorporates all of the public comment that we received during the public comment period as well as feedback from some of our

federal stakeholders and other partners. And we currently see this as broken up into, right now we have, nine sections.

So, and again, here and we can provide a little bit more clarification on this document as you share it out with others is again the “we” here is referring to the tech developer and the “you” and the “your” is referring to the user or the consumer.

So, I guess, quickly, we have several different sections, we have one how we use your information this is really focused in on how the information both your identifiable personal information as well as your de-identified aggregated and statistical information how that is used internally by the company.

And then also the next section is how we share your information, this is again how those different data...that information is shared to external parties and third-party providers and for what reasons.

We then continue onto our third section which is how we store your information, is it stored locally in the device or App, is it stored externally and then also is it stored outside the US and these are very simply yes or no questions and again there would be a link to the privacy policy for people who wish to learn more.

We also have a section on how we protect your information thus the technology encryption data, yes and no, and again, the link to the privacy policy there for more information.

We have another section on how this technology accesses other device data. So, again, this has come up a lot in terms of a very big concern for consumers around whether or not their device is actually linking to other applications such as the phone’s camera or other contact information and so we have that here as well and then also does the technology connect to social media accounts like Facebook.

The next section is what can you do with the data that we collect, this is really focused in on what the consumer can do with the data. So, we heard back from the commenters that they thought that this would be something that consumers would be interested in so basically there how...if they have access to the data and if they can edit and delete their information. If they can share their data with others such as their family and friends or through social media or to doctors and providers that is here as well, as well as what happens to the data when you deactivate or terminate your account.

We also have some sections here at the bottom about how consumers would be notified in other various cases such as if their privacy policy changes as well as in the case of a breach or criminal activity.

And then finally, what was suggested was to include...from the comments, was to include some contact information from the company on how others could connect with them with additional questions. So, we have here, again, there a mailing address, e-mail address and then the link to a full privacy policy.

So, that is the rundown of this draft in a nutshell but, again, we would love for all of you to take more time with it to really look at it and again we’re really focused in for this group, as Mike has suggested, is that we really want this group to really focus in on more of the consumer side of this notice. Is this something that...is the language clear, what is missing, what other things are consumers concerned about when it comes to privacy and security that either isn’t here or isn’t clear. Is the language, you know, really speaking to folks and really is clear and in plain language and if not how can we make it clearer for consumers and how can we simplify it, you know, we want to make this something that,

again, that consumers could easily look at and very clearly see and make decisions based on it. So, we would love your feedback on that as well.

So, we will be providing, after this call, with some additional sort of guiding questions to help you as well as those that you are outreaching to help look at this notice and really appreciate all of your really thoughtful feedback on this.

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

Okay, thank you, I mean, just looking at it, it looks fairly clear, but, you know, those of us that live in the IT and informatics world some of these terms are very familiar for us so I think it's a good idea to get some folks that are maybe outside what we do every day to take a look at some of the words like "aggregate" and "de-identified" I'm thinking, you know, people would look at that and think "I've no clue what you're talking about."

So, okay, so the next steps then Margeaux are going to be that you're going to send us some specific questions that we're going to take a look at this document in addition to some public feedback that's already been submitted is that correct and then provide some answers to some questions and some feedback on this?

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

So, the...we are opening up for public feedback and we'll be hopefully getting some comments through this Consumer Task Force, you know, being a public meeting, we would love to kind of get some public comment on this by the 15<sup>th</sup> and so hopefully by that date we will have some submissions and we can aggregate those and send them out to the group.

In the meantime Task Force members please go ahead and start looking at the document and really diving into it and providing us with any sort of more, you know, when you have a little bit more time to look at it any sort of feedback on that as well we welcome that before the 15<sup>th</sup> but also we know that we would like that by the 15<sup>th</sup> to again have those public comments in and then have that provided to the Task Force members to incorporate into their comments and to help kind of inform the comments that you'll be submitting.

In addition to that, we would love for your help with...and we really appreciate everyone already your support to, you know, share this with others that you may know of that are connected to either consumer groups or who might have some touch with consumers to provide some additional feedback on this as well.

I think and then again we'll be coming back on the 27<sup>th</sup> with that feedback to then report out to this group of what you all said on the comments and the content, and then from there we'll develop sort of those sort of recommendations for the general comments from the Task Force.

With that I want to just also turn it over to Michelle and Mike to see if there's any additional clarification they wanted to add to that timeline?

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Sure.

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

Yes?

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Well, yeah, I think, there might be a little bit of clarification on the work plan, like the feedback on the 13<sup>th</sup> that is not for the Model Privacy Notice, right, that is for the other work?

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

Yes, that is not.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Yes.

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

So, that is...

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

That's in preparation for the meeting.

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

The Joint Meeting...

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

Sorry, Margeaux, 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**

Where Patty and Donna will be presenting on the previous work that they did on the Patient Engagement Playbook and the Connector.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Right, so, looking at that work plan and so you have the Model Privacy Notice now you can begin your own evaluation of it and then I appreciate...I heard from many of the members already that they'll, you know, let us know where to send...where public can send their comments and you'll definitely disseminate the word about that so that public comment we're hoping back by the 15<sup>th</sup> and just so you

understand the reasoning behind that if I didn't hit on this already is that this gives you time to look at those, that feedback, which may inform you view either support it or maybe change your view and then when you provide us then feedback on the 27<sup>th</sup> would incorporate that as well and then, you know, as Margeaux said, you know, where you can use members who are, you know, consumers that use Apps and you can test this out with them so to speak and get their feedback that would be great as well...and I'll...

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

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**  
Michelle or Margeaux are we going to try to provide some type of like e-mail or is it the Federal Advisory Committee e-mail that they have that people would be able to send to public or we'll work that out afterwards?

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**  
Yeah, so public comment always goes to the generic FACA mailbox which we display at the end of the meeting.

**Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**  
Okay.

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**  
I think we've been a little bit confusing about what's due and what's not so I just want to send...we'll send a follow-up e-mail to all the Task Force members with a more clear timeline and exactly what we're asking of you and we'll also include that e-mail address for you to share with others so that we can get more public comment. Margeaux, did you want to add anything?

**Margeaux Akazawa, MPH – Presidential Management Fellow, Office of eConsumer Health, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology**  
No, I think you captured that, so, yeah, so look for an e-mail with more clarification, again, I'm sorry for being so confusing, but we really appreciate all of your help with this, you know, to Leslie's point we really want to make sure that this is something that really speaks to consumers that is consumer-friendly that addresses their needs, their topline needs when it comes to privacy and security of their data, so we really appreciate the feedback on this and look forward to hearing what you all have to say about it.

**Patricia P. Sengstack, DNP, RN-BC, CPHIMS – Chief Nursing Informatics Officer – Bon Secours Health System**  
Okay, great, thank you, so Michelle, do we need to open the line for questions?

**Michelle Consolazio, MPA – Federal Advisory Committee Program Lead – Office of the National Coordinator for Health Information Technology**  
We do. When we went over the...well, let's open up the lines. Operator, can you please open the lines?

## **Public Comment**

### **Lonnie Moore – Meetings Coordinator – Altarum Institute**

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

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

So, while we wait for public comment the e-mail address for the public to send their comments is up on the screen, if you're just listening it's [fac-a-nc@altarum.org](mailto:fac-a-nc@altarum.org) for our Task Force members that's the e-mail that we use to send out most invites and what we distribute emails from so you should be fairly familiar with that e-mail address. It looks like we have no public comment so thank you all for your patience with us as we navigate this process.

As we mentioned we'll follow-up with an e-mail to clarify any areas of concerns. We'll also send out the summary that Stephen spoke to earlier in today's meeting and I hope you all had a great summer while we had a little bit of an reprieve in August and this will certainly be a way to get you back in action and, you know, we're getting you started getting right in there with some homework so, thank you all who joined today, we actually ended up having a pretty good list of members that were able to join by the end of the call, so thank you and thank you Mike and Stephen for joining us today. Have a great day everyone.

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

Thank you, bye-bye everybody.

### **Mike L. Lipinski, Esq. – Director, Division of Federal Policy & Regulatory Affairs – Office of the National Coordinator for Health Information Technology**

Thank you, bye.

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

Thanks, everyone.

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

Bye.