



Collaboration of the Health IT Policy and Standards Committees

Consumer Task Force

Final Transcript

July 12, 2016

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

Donna R. Cryer, JD – Principal – CryerHealth, LLC

Here.

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

Hi, Donna.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

Hello.

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

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. Allie Foti?

Alisa Foti – Health IT Policy and Outreach Coordinator – National Partnership for Women & Families

Here.

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

Hi, Allie. Angela Kennedy?

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

Here.

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

Hi, Angela. Brian Ahier? Carolyn Kerrigan?

Carolyn Kerrigan, MSc, MD – Professor of Surgery – Dartmouth-Hitchcock Medical Center

Here.

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

Hi, Carolyn. 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

Hi, George. John Derr?

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

Here.

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

Hi, John. Kevin Fowler?

Kevin Fowler – Consultant – Kidney Health Initiative

Here.

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

Hi, Kevin. Leslie Kelly Hall?

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Here.

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

Hi, Leslie. Susan Brown? And I believe Suzy Hull is not able to join. From ONC we have Margeaux and Lana is anyone else from ONC on the line? Okay, with that I'm going to turn it over to you Patty.

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

All right, very good, okay, thank you very much. So, welcome everybody and I think at this point we don't have anybody new on the call that has not had an opportunity to introduce themselves so I don't know that any formal introductions are welcome so we will dive right in. So, we've got an hour and a half today to review the feedback on chapters three and four of the Patient Engagement Playbook.

Just a quick recap, last time we met we talked about chapters one and two, we had some great discussion, lively discussion and so we're moving onto chapters three and four, so looking forward to today's discussion and I'm thinking, you know, if we're really on task and focused we'll be able to give some people some time back today, I'm not sure that we need the entire hour and a half but we'll see how things go. Then we'll review the work plan and discuss our next steps.

So, for anybody who is following along not on the webinar we are on slide 2, but I think we can go ahead to slide 3. Again, this is just showing our members and I think we've got more people than we did the last time, so maybe not as many people on vacation this week, so this is good, I look forward to the conversation. Next slide.

Okay, so before I turn it over to Margeaux to just give a quick review of our charge and our work plan I'll ask Donna is there anything you want to share with the group or any input or words of wisdom for us as we dive into chapters 3 and 4?

Donna R. Cryer, JD – Principal – CryerHealth, LLC

No, I just wanted to...except to thank everybody for the diligence shown by all the homework and comments we really appreciate that, so otherwise, thank you Patty.

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

Yeah, we had lots of good e-mails going back and forth with great input. So, as I'm...well, I'll wait until we come back on...okay, so is it Margeaux are you going to take it over here for us?

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

Certainly, thank you so much Patty and Donna and just to echo you guys, we on the Consumer Team, really, really appreciate everyone's really thoughtful and thorough feedback of the Playbook thus far. Your feedback has been really, really valuable and we really are looking forward to incorporating all of the thoughtful discussion from these calls as well as what you have provided in the homework for future iterations of the Playbook.

So, again, as you know, this Task Force is to provide insight on ONC and HHS projects and initiatives with a consumer focus and the Patient Engagement Playbook is just one of these projects. And I will go ahead and go onto the next slide.

So, here is our work plan, just to kind of recap on where we have come and particularly for those who may have missed some of the previous calls, so we did kick off with a demo of the Patient Engagement Playbook that we provided for all of you and then provided you guys with some homework to do and provide us with feedback that broke up the different chapters.

The last meeting we did discuss the introduction to the Patient Engagement Playbook as well as chapters one and two, and again, thank you so much for everyone who provided feedback on those, we really appreciated it, and today we'll be discussing chapters three and four, chapter three, allowing caregiver proxy access and chapter four, integrating patient generated health data.

For the next meeting that will be upcoming, next week, we will be closing out our feedback with a discussion of the overall Playbook and just to note in the homework assignment there are a little bit different questions for the overall feedback that we would really love for you all to address.

Then we will have some meetings in August as well as September that we will be discussing a little bit more but hopefully kind of maybe gathering that feedback and then we will be having our Joint Committee Meeting on September 13th and we hope to be able to share some of the feedback that you have guys have given us through this exercise of looking at the Patient Engagement Playbook in a more formal fashion there. So, with that I will go ahead and turn it back over to Patty and Donna.

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

Okay, very good, so this is Patty, today I'll be facilitating our discussion and we can go ahead and go to slide six which I believe shows the summary input from chapter three. So, first of all to the ONC team, thank you so much, I know you guys are always scrambling especially for us who submit our homework at the last minute to put together a summary of what we have provided, so what we're looking at now on slide six are some of the main bullet points that ONC has pulled together to summarize our input.

So, as I'm looking at these, you know, they're fairly high-level, you know, just sort of looking at things that might have been redundant or, you know, things they've heard from multiple people that they've listed here kind of in the summary fashion not the detailed comments that people submitted.

So, before we dive into this, and I'll go through them briefly in a second, I'm thinking that what we all need to do is to, you know, pull up your...on another screen, pull up your input that you submitted so you kind of have that as a reference point. I've got a couple of things going here, I've got my list that I submitted for chapter three on another screen as well as the actual Playbook itself so when we have this discussion I've got kind of all this in front of me so we can have a good discussion.

So, anyway, so chapter three, some of the feedback summarized on the slide, you can see...none of this is probably a surprise to you, so a lot of us thought that it is an important issue and the whole proxy issue of being able to access, you know, the health records of our loved ones and how HIPAA...most of us liked how HIPAA was addressed because we all know that's very important.

Also feedback they got shared that the examples were good, always good to have a video, some real life examples from some organizations were helpful. Some of our members suggested that more examples would be helpful and maybe even testimony of the proxy access for a child or an elderly patient or parent, because if I'm remembering correctly, and I'd have to toggle back to it, I think the two examples

were for adolescence and so it would be helpful for maybe other examples for a child or an elderly patient or parent.

Okay, members also stressed that there is not enough evidence for how caregivers make decisions and why it is important to make patient portals accessible. So, maybe more of a, you know, kind of why it is important, a little more stress on that.

Members also felt the language was a little dry, maybe a little wordy, maybe it could be just a little simpler, a little more engaging, maybe some more links to some resources on those privacy laws because sometimes they can get complex.

Also, members suggested a few things, so more illustrations, more things like infographics, more animation, vignettes to make it a little more interactive and interesting. And maybe someone suggested that the title can be a little bit simpler and some recommendations that were thrown out there were access for patient's family, caregivers and others and we just call it exactly what it is.

And maybe, you know, if somebody can comment on this later, that maybe the word "proxy" is confusing, maybe we think that people won't understand that term. Also, another suggestion was allow for a title to allow authorized caregiver access.

Another comment was to make language refinement to reflect...oh, somebody needs to go on mute, make language refinements to reflect some of those nuances of the privacy laws as it relates to the data sharing with the caregivers, boy that can be complex and anything we can do to make that clear I think would be helpful.

Then a lot of the discussion talked about stating that there are rules, state the state, so like Maryland, Michigan, Florida, etcetera those state rules and regulations can sometimes dictate proxy access and wondering if it might be possible to provide some links to those so that people aren't just left hanging out there with what their state requires.

And I don't know if ONC you had any other comments about, you know, how you decided to just pull these, because I know there was a lot of e-mail that went back and forth on chapter three and I'm not sure if you wanted to make any kind of a comment on the things that you selected before we dive in? So, would that be Margeaux or...

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

Certainly, yes, I'll speak to that and Lana, please feel free to jump in as well. For these slides, and again, we did receive a lot of comments and we really appreciate it. For the purposes of the slides we tried to aggregate the information that we heard pulling out some of like the really kind of...the common things that we were hearing as well as the things that we felt like we could kind of...could lead to also some additional discussion.

Some of you had some really nuanced points around things like, you know, changing, you know, either...we could change the wording here or this color, or other things that were still very, very helpful but that we're going to be...we will be forwarding to the team to make those edits, but we felt that might have gone a little bit too much into the weeds and particularly for the discussion today but just

wanted to let you all know that even if you don't see some of your comments reflected on these slides that we are still incorporating that into...and forwarding that to our team that will be making the edits for the next version.

But I just wanted to say that that's kind of the way that we went about drafting these slides really trying to find those either common themes or those points that people brought up that we felt like could lend to additional discussion that kind of were a bit broader issues around not only the view, the look of the Playbook and how it...user experience but more generally about the whole topic and the content that was in it.

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

Okay.

Kevin Fowler – Consultant – Kidney Health Initiative

This is Kevin, I'd just like to ask somebody, this certainly captured my comments, the only thing I would just add to it is it just seemed like it was written by an attorney. So, I felt like my former days and it is like "oh, my God, this is a flashback." So whenever I hear attorney it doesn't connote anything positive so for what it's worth.

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

Oh, dear, that's funny.

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

Do you feel like...

Kevin Fowler – Consultant – Kidney Health Initiative

It's true.

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

Sorry, this is Margeaux, I would love to ask a little bit more about that. Do you feel like the language was just a little bit too jargony and legalese? How would you suggest to make it easier or more accessible and less...

Kevin Fowler – Consultant – Kidney Health Initiative

Yeah, I mean, I don't know what your vetting process is but I would just say, you know, I'm not a physician, right, so this is supposed to be geared towards physicians, correct? So, if that's your audience, I mean, my sense is getting some feedback from the end-user there, so, you know, you're getting...this is a patient perspective, but I would just suggest getting some feedback from physicians and see what they have to say.

It just seemed to be so much like a...it was, you know, communicating like a regulation, because I think overall the intent behind all this is really great and I think we're trying to help get these doctors to begin

to understand, you know, we're in the midst of a lot of change and why change is important, right? As much as people don't want to change they have to. So...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie, I would agree with Kevin on that, I think it's just too technical in terms and it is written more like a regulation language not a lot of plain language and also just getting at, well, why is there a proxy access, why is it important to me and why shouldn't I be afraid. There is a lot of fear around...

Kevin Fowler – Consultant – Kidney Health Initiative

Yeah, I think...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Whether you give people access or not that's not even addressed in here.

Kevin Fowler – Consultant – Kidney Health Initiative

Well, yeah, and I think if you look at this as pragmatic, right, I mean, just to think about this in a different context, so, if I look at, you know, going through, you know, transplant or let's say I've had some other health issues, my wife has been instrumental in helping out in that initial phase so it's just common sense, right, that another person is going to assume more responsibility and that's going to vary by different diseases.

But I think that partly is what you're trying to do is to get the...not only can doctors begin to understand the patient's point-of-view how that is going to help improve their efficiency, right, rather than constantly calling back to the staff and asking these questions this is a natural process of a patient's journey.

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

Kevin, if it helps I can speak from the doctor perspective, I agree with you in terms of, look I can read this and I have some experience so, you know, it made sense to me, but if I was day-to-day practicing and trying to see patients, you know, I may understand some of it but I'd say a lot of it would be over my head.

And it's not so much that I couldn't eventually sit down and try to figure it out it's just between that and the probably 300-400 tasks a day I have in terms of coding, billing, calling people with labs and whatnot this would probably fall very low on the list.

And again, it's not anything more than an observation but, you know, typically for most user experience type stuff I thought most of this was geared toward somebody at an 8th grade level kind of reading comprehension not so much that you under estimate people's ability to comprehend things but just that it makes it easier to apprehend the data and the information. Maybe that's the same lens that should be used for some of the language here as well not because it's focused towards doctors but it will allow them to at least skim it, understand it, process it and figure out what they're supposed to do next. Kevin does that...

Kevin Fowler – Consultant – Kidney Health Initiative

And I think...

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

So, this is Michelle, just a reminder, if you could state your name before speaking, was that last speaker Brian?

Brian Ahier – Director of Standards & Government Affairs – Medicity

No, this is Brian, sorry, I was late getting on and so I've been just quietly listening, but I haven't actually spoken until right now.

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

That is high praise though you thought I was Brian, I appreciate that, this is George from the...

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

Oh, sorry, George, okay, thank you.

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

Yeah, I'm the HP guy, I'm just going to say that.

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

So, and you guys...

Kevin Fowler – Consultant – Kidney Health Initiative

And...

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

This is Patty, I just want to focus us just for a second, so it sounds like we've just sort of navigated towards, you know, ONC asked us really specific questions and the one I think we're sort of navigating towards is what would you change about this chapter, so I love it let's stay on this theme for a little bit until we feel like we've all kind of, you know, had our say. And so what would you change? Are there other things that people would change?

Kevin Fowler – Consultant – Kidney Health Initiative

The tone.

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

That what?

Kevin Fowler – Consultant – Kidney Health Initiative

The tone.

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

The tone? Okay.

Kevin Fowler – Consultant – Kidney Health Initiative

Yeah, I think any time you start hearing attorney I immediately take that item and throw it away.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

This is Donna laughing as an attorney, I understand.

Kevin Fowler – Consultant – Kidney Health Initiative

Nothing personal Donna.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

Can I ask the group a question as your friendly neighborhood attorney, if we simply remove the word “proxy” would that sort of make everything else a little more friendly and accessible? If we simply talked about, you know, use the terms or the examples, or use caregivers or others and never use the word “proxy” which I absolutely agree with the group on, just never use the word “proxy” in this space and simply say “allow caregiver access” and go from there. Would that sort of cure 80%, 90%, 100% of the problem with this chapter?

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

Well, this is Patty, I think that, you know, that would certainly make it clear but the problem I think is that a lot of the vendors use the term proxy when you’re setting it up. You know what I’m saying, so, you know, we could not use it in this document, in this tool but then when you actually go to set it up I believe some of the vendors use the term, you know, proxy access. So, you know...

Donna R. Cryer, JD – Principal – CryerHealth, LLC

So, then we...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie we could just simply say caregivers, friends, family members or others, we refer to them as “proxies” for the patient as...

Kevin Fowler – Consultant – Kidney Health Initiative

Advocates.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

Yeah.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Another way to explain it.

Kevin Fowler – Consultant – Kidney Health Initiative

Advocate.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

So, take it out of the title but then explain it later on and then continue to use the term unless we're using, you know, the specific example that's cited where, you know, the term has to be used because that's what the vendor uses, but otherwise explain it upfront but not have it in the title.

Kevin Fowler – Consultant – Kidney Health Initiative

I think that's...if we look at this document as a living, breathing document we also want it to be a trusted advisor for providers and patients just as you all took the time to kind of explain, well, this is how a vendor might define what a proxy is or might use the term maybe that's how it should be referred to in the document as well. It would, I think, engender a lot more trust.

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

Yeah, I like that, I like that. I'd also note, this is Patty again, I'm looking at my notes that I sent in. I also noticed that it states that you can "work with your EHR vendor to make sure you can give each personal representative a unique secure login to access the patient's portal." And I'm wondering sometimes you're not working, the providers aren't working directly with the EHR vendors, you know, the larger systems are working with their informatics teams and not with their vendors. And, you know, George I don't know if, you know, your experience is different but I know all the doctors in our markets they're not working with the vendor at all they're working with our, you know, our IT or, you know, our EPIC.

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

I mean, you're right basically maybe somebody in the leadership like one of the physician executives is probably dealing with the vendor to give opinions, but when they start doing the installation of like an EPIC, right, that's when you start having physician representatives a few layers below that will start dealing with the teams to set it up properly.

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

Yeah.

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

But you're right it's not like every single doctor gets in there and interacts with the vendor directly.

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

Right, yeah, okay. Other things that folks would change with this chapter and, you know, I'll also add in there, you know, things that are missing so that kind of encompasses two of the questions that ONC is asking us. So, things you would change, things that were missing? Other thoughts from people who haven't spoken yet? Okay.

Okay, so then one of the other questions that they wanted some feedback on, let's go to the other side, is what do you like about this chapter? What are some things that are working that we don't want them to change? Are there some things that we would like for them to keep?

I know I have written down in my notes the examples. I liked the UCSF example. Other thoughts? Did I lose you all?

Donna R. Cryer, JD – Principal – CryerHealth, LLC

We're here.

Brian Ahier – Director of Standards & Government Affairs – Medicity

I think we're all being very thoughtful before responding.

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

I thought, oh, my gosh my phone got cut off.

Brian Ahier – Director of Standards & Government Affairs – Medicity

Well, one thing that I think is really helpful, you know, and it's used throughout the Playbook, is sort of patient stories, right, that include video or, you know, an infographic that describes in a visual way what this is all about and that might be interesting to have here.

You know when we're talking about the caregiver access for instance if you're caring for an elderly parent or a disabled child, you know, you obviously want to get access to their information but if it's a parent you have to have the right to do that you can't just walk in and say "give me my mom's medical records" that doesn't work. So, maybe a use case that shows this actually working and people that are taking care of family members or others that now get access and similar to some of the other things "oh, look at that there's a lab result" or something and in many cases you have to have a caregiver doing that because the patient themselves wouldn't be able to understand it.

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

Do you think it is clear how they've explained how security can be set up so that certain things can be looked at and other things can be restricted? You know I think that the intent there was to alleviate, oh, sorry, this is Patty, the intent is to alleviate people's anxiety around being able to access a loved one's entire chart when only certain pieces are appropriate for sharing and I think the intent was to try to, you know, clarify that that's possible from a technical stand-point. Do you think they did a good job at clarifying that for folks?

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

Hey, Patty, it's George, again, just my opinion I think it's there. I think the issue that at least I saw was that it is in there but it is very wordy and as I said, typically people tend to skim these things and they may miss the important sections that are relevant to them understanding a key point like data sharing or control of data sharing. And to Kevin's point, maybe something that's more, you know, kind of an illustrative example or an infographic of some sort where it simplifies it would allow them to understand that, no you have control over your data and you can control who sees it and who doesn't.

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

This is Angela, I have one comment and this is a little bit different but on that same line, I know that we don't want this to be too much use of legal terms but we talk about the Power-of-Attorney being used and this presents well for a patient or a provider and I think it is very well presented in terms of HIPAA and what they need to know and for training purposes should be a very good document.

However, there is one thing that kind of bugs me just a little bit. We talk about the Power-of-Attorney and we assume that the reader of the document will understand that the Power-of-Attorney is only good when this person is alive and we don't lead them or link them, or say anything about, you know, or make any special notes that this is no longer a right after the person expires. So, I don't know if that is something we want to consider here as a part of this but, you know, you do have medical record uses for billing, for death certificates, for all other kinds of purposes after the person has expired, I don't know if there is a place for it.

It certainly would be good when you're talking to physician's offices in terms of training and maybe in a skim that's not something they want to know. So, just...I'm just thinking out loud. I'd be interested to hear what others think about that.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

This is Donna, I absolutely agree that if we are going to mention terms like Power-of-Attorney, which there are multiple types and they have multiple effects even depending on your state, that we should link to some type of resource that would help guide people through what's available and relevant for them.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

And it is important to note that a Power-of-Attorney isn't necessary to get proxy access that's only about consent of the patient. So, they might even have proxy access after the patient has expired, this is Leslie, sorry, so they're not one in the same but I think we should clarify that.

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

Perfectly stated Leslie, thank you.

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

This is John Derr, I just have a problem because HIPAA is so complex that we might scare people if we make this too complex. I thought it was nice and simple and short because HIPAA can be long and complex and if we keep making it more complex it scares the devil out of people and what our main goal is really to get people engaged and if we can just keep it and say here's five points that you can do and just keep it that way and then use the illustrations as other people have said and some patient's testimonial type of thing that they can relate to otherwise we might make it so complex it will scare people and will start defeating our whole goal which is to get the physician's office to engage the person.

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

Yeah.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

This is Donna, I agree with that point with a bias towards simplicity. I also wonder about giving the audience for this if the video should be around a provider interacting with a caregiver and that process being made easier, conflict being avoided for example, you know, if we gear the video towards using some problem of the provider.

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

Hey, Donna, it's Patty, I like that idea and I think...

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

And this is John Derr I like that too because I was just looking at it again and it looks like it's from the patient's point when really it should be from the provider point.

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

Yeah, I think the resounding theme here to our ONC partners is simplification and engaging examples, you know, I think we've heard that several times and I'm looking at the input people e-mailed we saw that again and again. Anything else that folks would change, think is missing or you like about this chapter?

This is still Patty, I'll just...one question I have for you guys before we go ahead and move onto chapter four I think unless, you know, anybody has anything else, I really like, on all the chapters the "share you feedback" button and I'm curious if you've gotten any on this chapter or, you know, maybe you don't know that right now, but perhaps in our next meeting in our last meeting when we're looking at the overall piece you could share with us any feedback that you've received. I was just curious if anybody has, you know, actually clicked that button and provided anything. Do you know off the top of your head?

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

Patty, this is John Derr, I mentioned once before I think that section the start over, share it with others, would others find this information helpful should be after the examples because it tends to end the session when as we've said in all the meetings how valuable the examples are at the bottom. I would put it at the end not in the middle.

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

Okay.

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

Hi, this is Margeaux, to answer your question Patty, we have been receiving a lot of feedback on the Playbook from other people who are using that function and that's a great suggestion so we will definitely see as a team what we can pull from what we've been generating and see what we can share with the group if that would be of interest to folks.

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

Yeah, I think it would be. I'd be interested to see if the feedback that you're getting is similar to, you know, what we've been saying. So, that would be great, thank you. Okay, any...so I'll say last call for chapter three anything else, anyone in looking at your notes, anything else anyone wants to share before we move onto chapter four?

Okay, all right, so chapter four, again we have the same questions, the first impressions, content, engaging, what do you like about it, what would you like to change and I'm going to pull it up too, I like to have it in front of me open at the same time. So, we're talking about patient generated health data. So, maybe we'll start this conversation with the, what did you like about it, what do you think worked well for this chapter? So, chapter four.

Kevin Fowler – Consultant – Kidney Health Initiative

The examples were very good.

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

Lots of them, who was that who just spoke?

Kevin Fowler – Consultant – Kidney Health Initiative

Oh, I'm sorry, I apologize, this is Kevin.

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

Hi, Kevin, yeah, there were some really good examples there weren't there, several of them.

Kevin Fowler – Consultant – Kidney Health Initiative

Yeah.

Alisa Foti – Health IT Policy and Outreach Coordinator – National Partnership for Women & Families

This is Allie Foti, I just wanted to support that in saying that I think particularly with the first example not only the evidence, the quantitative evidence, that supported the benefits of incorporating patient generated health data but also the testimonials really made that particular example quite strong.

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

This is John Derr again, I did put in mine, I know that it's hard to get quantifiable information but in today's world 2013 it is pretty old and maybe a projection of what it would be in 2016 rather than doing

something that is three or more years old, because I'm sure that number is a lot more now, maybe 2 in 5 or something like that or make some statement like that.

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

Okay, so are we...so is there any...before we move into what would you change are there any other things that we want to tell ONC to keep that we liked? So, we've said the examples from other organizations was very helpful, other things that...I mean, and I'll just echo what I've said about all the other chapters is the ability to provide feedback at the end I think is always very helpful. Are there other things that people liked? Let's do the positive and then we'll go onto the things missing, things we'd change.

Alisa Foti – Health IT Policy and Outreach Coordinator – National Partnership for Women & Families

This is Allie, again, I'd be really interested in hearing the group's take in that. I found in particular this chapter to have steps about how providers could engage in these strategies to be really tangible and actionable. Often I think we talked about attention in that many of the chapters require engaging with EHR vendors and some absent step that maybe completely outside of the control of providers and I found these steps about change in workflows and engaging with practice staff and with patients to be particularly tailored to providers and I wondered if the group thought that these steps were strong.

Carolyn Kerrigan, MSc, MD – Professor of Surgery – Dartmouth-Hitchcock Medical Center

This is Carolyn Kerrigan, I agree that they are strong and this is going to get a little bit into suggestions. I think one of the biggest concerns that providers would have in reading this is like "yikes, this is going to be a ton more work for me." And I don't think it jumps out here really how it is the full care team that's going to be looking at this data, this is a big role for health coaches and chronic disease management. So, as I said, this is more of an improvement rather than, you know, what I like about it currently.

So, I just think the emphasis needs to maybe shift a little bit away from the generic term "providers" so that physicians don't see this as largely being their role or they're the only one looking at the data.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

This is Donna, what word might you suggest could convey that or is it not to sum it up in a single word but to include specifically the various categories?

Carolyn Kerrigan, MSc, MD – Professor of Surgery – Dartmouth-Hitchcock Medical Center

Sort of towards the end of the main text before the examples the third point is develop policies and procedures like when to accept data and who will review them I think that's really key and I think...but throughout the term "provider" is used and I think just thinking more about, you know, is the main...who is the main person from the team that's going to actually manage this information and my inclination is to think that it's going to be, you know, health coaches or care managers who will triage the data and then feed to providers.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

I wonder if...data that demonstrates even currently...I know at such an early stage of wearables and other sort of ways of presenting patient generated health data to practices, but who usually interacts with that data. I know that, you know, there's data showing that physicians are concerned that they would be flooded with a lot of data points and so they often request or, you know, comment on the

hope that this would be implemented through some type of alert system or triage system. I just wonder how much that reflects the reality today and if there was any data about that.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie and most often the data comes in just like any other observation or results coming into an inbox to be reviewed. When the information is coming unsolicited like an e-mail or other it does take a much more considerable review but most providers who are using a questionnaire approach to say “what are the medications you’re taking, what are your histories, what’s your observation of daily living, do you have any errors that need to be corrected” those kinds of Q&A structure can be very, very helpful because it comes back in a way that is codifiable and so is easier to put into the record.

So, when we heard testimony I think three years ago on patient generated health data the areas that were the most important to the provider was medications and histories, the drugs they’re actually taking not what was ordered and side-effects, one doctor, I think it was from Geisinger said “I didn’t want to do patient generated health data, I didn’t want any part of this and now I’m a better doctor.”

Donna R. Cryer, JD – Principal – CryerHealth, LLC

Yeah.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

And he said “that’s what it takes to be informed.”

Donna R. Cryer, JD – Principal – CryerHealth, LLC

That’s my understanding that it actually does go to the physician. So, I was just trying to find out if there...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Or the front desk, I mean, the front...

Donna R. Cryer, JD – Principal – CryerHealth, LLC

If...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

Yeah.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

If there was data to support that it went more often to coaches or other members of teams that may or may not exist in certain areas because in my experience and understanding the literature it usually does not for the majority of patients at this point or the majority of practices that it is used with the physician itself, him or herself.

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

This is George...

Kevin Fowler – Consultant – Kidney Health Initiative

...

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

I can comment on that too, that it does usually...depending on the situation, right, if you're a physician in the room and a patient brings in either their printout or some other type of format to show what they've been tracking over time that may or may not lead to a discussion, but, you know, I have to echo what other people said in the past, there is still a fear of "okay, I've got all this data is it reliable, is it actually measuring what it's supposed to measure and how do I use this to shape or direct the patient for their care."

And there are still...I hate to say it but there are still some doubt out there because there is what we know that we have clinical trials that we can reference and say "this drug does X, this surgery does Y" but for a lot of the trackers or even some of the adherence compliance, you know, a lot of that still is being considered subjective data. I mean, even Fitbit has gone to the FDA and considered themselves not a clinical tracker even though there are studies that people are using to determine people's attacks with it.

So, again, I don't want to be the Debbie Downer here, I think everything that we're doing is important to move the needle in getting providers to accept this data as part of the care. But in terms of how things are being done now, at least what I see at my level one trauma center as a doctor, that's how we're treating it.

Kevin Fowler – Consultant – Kidney Health Initiative

This is Kevin if I could just...

W

This is...

Kevin Fowler – Consultant – Kidney Health Initiative

Could I just amplify George's comments and this is from actual experience. So, just full disclosure there is a company I consult with and they have a patient engagement solution that we've been developing for the renal market which is, you know, greatly needed for improvement of outcomes, but the general sense or I should say the general challenge has been is that the first comment that comes up is...what you're saying George there is so much information, what do I do with this information, is this putting me at legal risk and so I think that that's what my experience has been. This is over a year or so what I've heard directly from physicians.

What I think would be helpful though is to then begin to...you know we're at the early stages of patient generated data, is what's the vision for patient generated data, right? How is that going to improve patient care for doctors? How is that going to make doctors lives better? I think that's the reality that I see and that's a sample size of over a year probably dealing with over, probably over a dozen to 15 different renal and transplant providers.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

And I think that the big barrier to patient, this is Leslie, generated data integrating it is the workflow issue because all data is patient generated data whether it's observations...

Kevin Fowler – Consultant – Kidney Health Initiative

Right.

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

From a provider or a written communication or coming electronically there is nothing that can be done without patient generated data. It's just a question of where that is in the workflow and how meaningful. So, perhaps what we could do is using the examples from Geisinger and others describe the use cases of where patient generated health data has really been useful to the providers and what we've heard more often than not is medication, history, side-effects, questionnaire and responses things that the doctors are asking to be kept current becomes more relevant it is just harder to deal with the perceived plethora of information because it's actually not been proven to be true of information coming in willy-nilly nobody likes information coming in willy-nilly. But when it is easy and computable, and integrated into the workflow those questions go away.

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

Well, to pick up on that one comment you meant, which is key, computable as well as part of the workflow is important. If you were to ask me, okay, I have a patient with chest pain I know what tests to run, I know how to interpret those tests and I know how that will change my decision-making, right? I'll do an EKG if they have chest pain, I'll do a chest x-ray and I know how to interpret that data that comes out because that will then change my differential diagnosis and how I direct the patient.

With the patient generated data I think that's the missing piece in terms of, how do I interpret it, how do I use it, how do I prioritize it and then how does that adjust or alter my workflow.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

I think those are indeed the questions, this is Donna, I think those are indeed the questions that physicians are asking and so providing specific use cases that address those can be helpful. You know it is astounding for me that physicians are satisfied with asking the question, you know, how have you been doing in the past six months, three months, one month whatever for patients with...diseases that there are and multiple variables and factors to track and they'll accept and answer of "fine" rather than an answer from, you know, a daily monitoring, you know, App that I keep that helps me track the symptoms, you know, symptoms in real-time. So, I think physicians need to ask themselves what they're really afraid of.

Perhaps a use case could be, you know, my orthopedics we use just simple step trackers to judge whether my cortisone injections were working or not because standards of care there is a conversation that says, you know, you'll come back and tell me when they don't...you know when it stops working. Well, that's very subjective but we can turn that into an objective thing instead saying, okay, how about when my steps drop below 4000 I'll come in for another shot, which is what we did. So, I think...and when we could no longer, you know, achieve, you know, a 4000-5000 step increase post shot we stopped doing them and instead moved to surgery.

So, there are examples of how, across the spectrum, from very simple, you know, to very complex of how patient generated health data can actually improve patient reporting, improve, you know, reduce the time of the visit and improve the quality of the patient/physician conversation and perhaps we need just more of those types of examples in this section.

Carolyn Kerrigan, MSc, MD – Professor of Surgery – Dartmouth-Hitchcock Medical Center

This is Carolyn Kerrigan again, I think I feel very strongly that we need to emphasize that this is care team, the whole care team's job, in the conversation that I've just heard a lot of great points but constantly referenced to the doctor or the provider.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

Because not everyone has an actual care team.

Carolyn Kerrigan, MSc, MD – Professor of Surgery – Dartmouth-Hitchcock Medical Center

I beg your pardon?

Donna R. Cryer, JD – Principal – CryerHealth, LLC

Not everybody has a whole care team with nurses and things that's a fabulous aspiration that happens in some places but there are many patients who don't experience...

Carolyn Kerrigan, MSc, MD – Professor of Surgery – Dartmouth-Hitchcock Medical Center

I mean, care team can be two people. I mean, I just think that for many providers the way our language now everything is sort of pointing to the provider's work and I agree that this requires new workflows but as much as possible using the care team more broadly.

You know and the question...the example just described about the step counter, you know, it may be that this orthopedic patient is followed by a physical therapist and it can be the physical therapist tracking those numbers with the patient as patient generated data that then alerts the provider when there is a change that is clinically meaningful and new actions have to be taken. It is not necessarily the provider, the doctor themselves that has to be doing all the tracking and the reacting. I think that's what creates the big push back from clinicians.

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

Yes.

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

This is John Derr and I think to build on that I suggested that this is really a two-way street that in our presentation in the Playbook there should be more saying get the patient involved because that's what our goal is to get them involved in their care so that they...and it is a two-way street not just a one-way street where it only puts the onus on the provider.

And as a patient on the workflow, two things, I'm a pharmacist so the doctors consider that I know more about healthcare than a normal person or somebody else coming in but in my oncology, which I see my doctors a lot, I track a lot of my own stuff and then I go in and I bring in all the charts, he's not capable of doing it electronically, which bothers me because my record is about 6 inches thick now in paper, but we

review all the stuff that I bring in and then he does change treatment especially on medications on me based on my treatment.

And my other feelings on my other doctors in my care team is, you go in and they ask you about your medications and they ask you how you feel, and as a patient I don't feel like they do anything with it. It is just sort of check off box and I think we have to get people to say, this is not just a routine you are important and what you're telling me is important and I'm going to use it somehow.

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

Hey, John, it's George, no, I fully agree with you and not just as a doctor but as a provider, as part of a team and again, not to cast aspersions on anyone, initially when this conversation started the assumption was that data was being brought to a doctor as a provider so that's how we were addressing it before, but, again, no assumptions made, anybody in the care team should be able to interpret the data, but I think John brings up a great point which is patient engagement is going to be key.

The example that I was thinking of, and this is where a lot of internists and primary care doctors come from, is the diabetic that tracks their blood sugar at home, the patient is very engaged and willing to track their data like a lot of type 1 diabetics are, you have better data from that patient than you would have from any device or any lab test you would ever run.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

Right.

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

They know themselves to the point that you can ask them and they know exactly how they're feeling when their blood sugar is low or when it's high even and that, in my mind, makes the relationship work to manage that patient's health they almost co-create their health together.

In contrast though, you have a lot of type 2 diabetics that may be on oral hypoglycemic or insulin and unfortunately that hasn't been the experience. A lot of people aren't motivated to track their health or their blood sugar. In fact sometimes they will go to the trouble of putting in false data and unfortunately as one of the providers on the care team we're still responsible for getting them well even if they don't give us good data which is why we run hemoglobin A1c tests to see how they've been doing for the last three months or we run a blood sugar and we check their blood weight or sorry their body weight.

So, what I'm saying is, I agree with everything that everyone has said and I think patient engagement is key but the reason that doctors are a little antsy about accepting all of this is that there isn't really a guideline or a task and not just doctors I think anybody in the care team should be a little antsy about taking just the data without assessing the patient as a whole holistically and saying, okay, is this person reliable, is this data reliable and I use this to a...

Donna R. Cryer, JD – Principal – CryerHealth, LLC

No, but I don't think anybody has ever asked...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

This is Leslie, I'm going to slightly disagree. I think that the...sometimes the most useful communication can happen because there is a conflict of what the patient perceives and what the doctor knows or because it's a difference of opinion.

I think that we are so used to the idea of reconciliation of data that we've forgotten the importance of curation and this is really a curation step that allows us to get new information to see where there is lack of understanding, to actually bring up new ideas and points. It's a great checking mechanism.

Could it be more uncomfortable for the provider because they're now getting new data points that aren't ones that they perhaps agree with or maybe think are true, but for the patient they're true and so it's important that we move beyond the idea of who is right and the idea of who is participating and how can we consider all points of view and so...

Brian Ahier – Director of Standards & Government Affairs – Medicity

So this...

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

This is Patty...

Leslie Kelly Hall – Senior Vice President of Policy – Healthwise

...

Brian Ahier – Director of Standards & Government Affairs – Medicity

This is Brian, let me just respond to Leslie's comments which I agree, I actually agree with what she is saying but I also agree with what George and John had been saying.

And maybe to give a real life, you know, real world example of this, there is a large payer that's partnered up with a medical device company and is using it in some of their accountable care and alternative payment model strategies for starting off with CHF patients and so they have home monitoring devices. One of those devices is a wireless scale because, you know, you want a daily weight and it goes straight into the EHR through that system and they've got other devices as well that you can have in the home that will interface directly with the EHR and send that information to the provider and to the care team.

But what they do is they verify that for...they check it so an alert comes up and says "wow, you know she's gained 7 pounds" you know, well, so they call the patient to verify it and say, you know, Mrs. Jones you weren't like holding onto your cat while you stood on the scale "oh, I was" well your cat weighs about 7 pounds. So, you have to verify the information.

If I call in and say to my doctor, wow, I just took my blood pressure, you know, and it's 160/95 that's high for me she would tell me come in and they would take my blood pressure, they would verify that my blood...they're not just going to say, you know, okay, that's good, let's get you admitted to the hospital. They would have me come into the office and take my blood pressure.

So, I think that certainly you want the patients participating and you want them to submit data but you also then need to verify. In order to provide clinical care you need to make sure that the data is accurate.

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

So, this is Patty, I'm just going to...great discussion. So, ONC is looking for some advice from us on this. So, is the...and I'm looking at the slide that we have up on the screen now that gives kind of the summary points from all of our comments that we gave them and I'm seeing, again, kind of a resounding theme and that is being able...that it doesn't provide a compelling reason as to why this is really important to the physician and then another bullet point is, the be clear on the what's in it for me and I think that's a lot of what we've been talking about and you guys have given some great really specific examples and so are we...would we recommend to them that the examples that are in there now maybe they're not clear enough, maybe they don't encompass the different scenarios.

So, I've heard also that, you know, sometimes it's a team approach where it may not be the provider that's the one that's actually looking at the data that it's somebody on the care team in coordination with the provider and of course I've got my nurse bias hat on I'm just saying that the nurse practitioner could be one of those providers.

And I'm also hearing that sometimes there is not a team and it's a solo provider who, you know, needs to potentially deal with this data coming in that's a little scary so perhaps we're giving some advice that there are examples and scenarios that are for that particular setting, you know, where it's just, you know, a provider without a team.

And so is that what I'm...is that the advice that I'm hearing this team giving that some of our scenarios need to be clarified and making sure that they cover the different sort of scenarios of team versus more solo approach?

Kevin Fowler – Consultant – Kidney Health Initiative

This is Kevin, I think you've captured it pretty well. I would just take a look at this too is that I think that decides the part about, you know, making the compelling argument, is that I think we have to be realistic and think about this we're not going to go from A to Z we've got to go from A to B and so like Kelly was bringing up different examples, I think looking at incremental steps so that one you have the look of what the ultimate hope and vision is but we have to think about the physician's practical world that they're living in and the practical world for patients and so what are those different incremental steps.

I mean, I can tell you, you know, if you look at the renal community, you know, I would just identify two areas that they're querying in terms of quality of life has been absent in dialysis, right, so there's a huge opportunity to improve that and then looking at kidney transplants still at 10 years half of them are failing. So, clearly, you know, those are areas with room for improvement where patient engagement, patient sharing, you know, data could be beneficial.

But I think it's just it has to be very clear and let's try to be pragmatic thinking about the doctor's view-point but this is not just going to be pushing a switch and everything has been transformed. That is the sense I'm getting from this, that's my opinion and I think we have to be pragmatic.

Alisa Foti – Health IT Policy and Outreach Coordinator – National Partnership for Women & Families

And to that point, this is Allie, I think that brings us back to Leslie's earlier point that there are compelling examples of health systems that are using patient generated health data right now to improve their delivery of care and that's namely around the capture of information on medications actually taken and side-effects and is that the first incremental step that we take in demonstrating that there is value in this patient reported data and then ultimately displaying our vision for the future of what that might be.

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

This is...

Kevin Fowler – Consultant – Kidney Health Initiative

I mean, I would just say specifically I think if you look at an issue of adherence, I mean, I don't know if that would be appropriate, but I find that's an area that cuts across almost all therapeutic areas and many times is being not really addressed.

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

This is John Derr...

Kevin Fowler – Consultant – Kidney Health Initiative

And that's a...

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

Go ahead, finish, Kevin.

Kevin Fowler – Consultant – Kidney Health Initiative

No, I'm done, John, go ahead, I'm sorry.

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

Well, I've looked at this little animation thing about three or four times just while we were all talking and again it doesn't really put...it puts all the onus onto the physician or the provider and I was just with two physicians yesterday talking about pharmacogenomics and how they can look at this report and both of them were saying to me "I can't do this John, you know, I've got five minutes, I've got eight minutes." So we have to put more onus back on a two-way street and I think that animation could say...offer ways or suggestions or maybe the examples to say, here's how you get your person, the patient involved so I can help you."

And I think the trending, you know, we mentioned a couple of things like this, with all due respect, on the blood pressure, but it's really...because when I went to my cardiologist she had high blood pressure but then I track my blood pressure and my blood sugar every day and I use trending information with my physicians and that because episodic, you know, foods done wrong or even in a PSA test there are certain things you shouldn't do before you have that test done, so I think trending and I think this animation could be more to the fact of where, here's some programs you, Mr. Provider, and the rest of

your staff can do to get your patient engaged and it is important and put more onus back on them helping them to get their patients or persons involved.

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

Thanks, John. Are there others...this is Patty again, so my other question from what I've heard over the last 10 minutes or so, it sounds like there are lots of examples out there that people have been kind of tossing around. Does the group not feel that the examples that are on the current Playbook are meeting those needs or do they...are you requesting that ONC look at those examples and see if they can be clarified in terms of who is responsible for actually the intake of the data, review of the data, analysis of the data. Talk to me about the examples that are currently there and what you would change or what advice you would give ONC on those.

Brian Ahier – Director of Standards & Government Affairs – Medicity

This is Brian...

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

This is George...oh go ahead Brian.

Brian Ahier – Director of Standards & Government Affairs – Medicity

Oh, go ahead. All right, well I just wanted to say that...so I'm on the...in the little animation on the part that says as EHRs become more capable of integrating more patient generated health data the potential benefits are huge. True enough. And then you click on the little plus signs and expand out into each category they talk about activity trackers that's commonly used by people, by consumers, you know, maybe it's relevant for certain conditions and it's always good information to have, but I don't think that's really where we're going as an industry when we look at patient generated health data and particularly mobile applications when we talk about the Apple Watch and other, you know, Fitbit has a watch now and it's really more of a smart watch than just an activity tracker and that's where things are going and they're embedding sensors in these devices that can do a lot more than just track activity.

Food and symptom diaries is a great example that they list there and then the other two devices that they talk about are home glucometers and home blood pressure monitors. That is just barely scratching the surface and things are moving quickly in this area. I expect that, you know, this would look old and out of date within a year and a half tops because of all the devices that are currently out there now. You can do an echocardiogram on your smart phone that's proven to be as accurate as going into see your physician. You can do pulse ox, you can do all kinds of things right from you device whether it's your smart watch or your smart phone, or a device that's connected by Bluetooth to your smart phone.

Then you can use open APIs to push that information over to your provider's EHR. And so that's where the industry is going and so maybe just keeping that in mind as I don't think that this needs to be updated now, this is certainly...it's all true enough and probably blood pressure monitors and glucometers are the most common clinical use case right now but just keeping in mind that the market is moving and you don't want...you want to keep this information in a Playbook fresh.

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

Yeah, so...

Kevin Fowler – Consultant – Kidney Health Initiative

So, let's play devil's advocate though, can I just for second. So, we talked about where the industry is going but does that necessarily result in improved patient care, right, I mean, I'm just going to play...view, but there is a lot of hype out there right now, but is this necessarily going to result in improved patient care.

Brian Ahier – Director of Standards & Government Affairs – Medicity

Well and so that's where I mentioned before about a payer that I'm very familiar with and I think George knows them pretty well too, who has partnered with a large medical device manufacturer, so two giant companies coming together in a joint venture, and it's public knowledge I'm not telling you any secrets, and partnered with another very large and prominent health system where they have care managers that are helping to improve care for patients, right, so this is the way it works when you want to move to value-based payments and, you know, start talking about quality of outcomes instead of process measures and they've found that it's digitizing that previous paper process because the paper process used to be the home monitoring device would send the information electronically to the medical device manufacturer's software and then if there was something that alerted them they had a call center with nurses manning it they would then contact the patient first to make sure that, you know, Henry, did you have your boots on the scale or, you know, are you sure that blood pressure is right let's do another one just to double check.

Then after they've verified the information they'd fax over a template, a form, they'd fax over to the provider's office and, you know, that's always an efficient great way of communicating important health information and then it works its way finally down to the care managers who take interventions based on the information they've gotten.

Now that information goes electronically from the home monitoring device directly to the clinical systems where the case manager and physicians can see it and act on it accordingly.

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

So...

Brian Ahier – Director of Standards & Government Affairs – Medicity

And they're not wasting...they're not spending a lot of money doing this because they don't think there's value there, they're obviously looking to lower costs and improve quality so that they're accountable care organization will succeed.

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

Right, so this is Patty, again, playing facilitator here in the meeting, so, you know, again I think what I'm hearing from everybody in your scenarios and real life experiences is that the advice, and tell me if I'm wrong, that the advice we probably want to give ONC here is that maybe the focus should be on patient generated data scenarios that have been tested that we do have evidence and provide, you know,

scenarios and examples related to those, kind of at the top, and focus on those but then in the same document, the same chapter, that we should also advise them to talk about some of the evolving uses of patient generated data but where the evidence is still not as clear...but not leave it out because we want to, you know, whoever is reading it might, you know, want to be kind of on the cutting edge. Is that what I'm hearing that the advice is to ONC?

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

Yes. This is George, yes.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

Patty...

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

I think that is the advice because, you know, again, we want to keep the most up-to-date information available for whomever the provider is to know that this is what's going on.

I was actually going to go with Brian's comment, I think, forgive me if I misinterpret it Brian, and if it's possible to organize some of the scenarios by condition allow it so that any provider if they're looking for how are people dealing with blood pressure, how are people dealing with obesity or trying to get more activity that would allow them to reference it or find that information because, you know, the thing that we're having the issue is, and I think you even pointed this out, there is a lack of good outcomes data beyond a few months for any of these trackers.

Brian Ahier – Director of Standards & Government Affairs – Medicity

Right.

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

Yeah.

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

And getting any provider to kind of sign off on it and say, you know, my EKG machine didn't work but, you know, they checked their Fitbit and I think they're okay, it's going to take some time for that.

Brian Ahier – Director of Standards & Government Affairs – Medicity

Yeah, well, you know, I the examples that they give in the Playbook, you know, Carolinas Partners HealthCare and they actually give some results of a four month program...

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

Exactly.

Brian Ahier – Director of Standards & Government Affairs – Medicity

Four month evaluation, you know, four months it would be nice to look at maybe that study, it would be good if they expanded that and, you know, look at how many subjects were involved in the evaluation and four months is not very long, but four months with the number of patients that they had showed, you know, a cut in the rate of failure related hospital readmissions, cut it in half, you know, so if you can prove that that's true you've got a lot of interest, there's a lot of people, you know, obviously it's for the good of the patients...

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

Right.

Brian Ahier – Director of Standards & Government Affairs – Medicity

But providers and health systems are very interested in cutting heart related, heart failure-related hospital readmissions and cutting it in half is pretty remarkable.

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

Yeah, no kidding and so...

Kevin Fowler – Consultant – Kidney Health Initiative

Hey, Patty, this is Kevin, I just want to say I thought Brian...that example Brian just gave was very good and I just think that you went through it very tangentially and went through those different...how this translates into, you know, really overall improvement so that is kind of like the vision but then we have to think about the incremental steps, right, so how we create that future that he's talking about that's how I think it will be effective.

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

Yeah and I'm not sure how to advise ONC on this chapter to illustrate, you know, something that for us and ONC to think about how to illustrate those...I agree with you those baby steps or incremental steps as providers move forward with this because somebody said it earlier it's not...you don't just turn it on and now you're doing all this wonderful and innovative patient generated health data work it is incremental and so my thinking is that we need to ask ONC to think about that in their next iteration of this.

And I'm looking at the time and so I'm going...I will ask in just a second if there is any other advise people have for ONC on this chapter in just a second but I want to ask ONC a question and that is where do you all get the scenarios that are on here? Do you...is it just people you know you reach out to or, you know, can we help you with some of the scenarios in future versions of this? Because clearly you heard from this group there's lots of work going on out there that might be good to include.

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

Hi, yes, this is Margeaux, and Lana please feel free to jump in for anything that I might miss, but as a little bit of background, yes, the scenarios that you're seeing on the first iteration of the Playbook were

pulled from, you know, things that we have been hearing here at ONC of best practices, using our connections and contacts to help build those examples.

So, with that we are all ears for any other examples or bright spots that you feel that you've been hearing from your own networks or that you would feel might actually help to illustrate some of the content a little bit better those real world examples of really some of the successful things that are happening we would love to get those examples. So, please send them our way if you have any that come to mind for any of the challenges or the things that you've been pointing out in these discussions.

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

Great, thank you.

Lana Moriarty, MPH – Director for Consumer e-Health, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

Yeah and I...Patty, this is Lana, I just want to add a little bit to that. Again, I think a lot of this has come from our background in the field with various stakeholders and partners, and, you know, hearing what's happening and following up on those connections and trying to get it documented.

So, even if the Task Force members have examples or things that they know of, you know, either within their own, you know, themselves or with their own health systems or their own providers perhaps even as a patient, good examples that may not be documented please bring those to our attention because we can then have staff interview, you know, the appropriate parties and stakeholders and get those documented in and developed.

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

Excellent, great, thank you. Okay, so, I'm just again looking at the time, I know we need to open for public comment, are there any last minute pearls of wisdom or bits of advice for ONC on chapter four?

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

Hi, this is George again, one last comment, please, and ONC team thank you for all work you've done on this by the way, this is more than any of us obviously could have done, so let me start with that.

If this is to be used by providers in the field then might I suggest that it should take the format of say an Army Field Manual or a Merck Manual, I know there are aspirational things in there where providers are asked to or encouraged to include their patients in tracking their data and there are...at least you're trying to give us examples of how to use it, but if I could, since I'm having a difficult time describing to you how this would be most useful to me and other people like me in practice, looking at some of these field manuals where they describe tasks and how things are done that would be of the greatest service to us if only so that it gives us some direction on how to use all this data as it starts coming towards us.

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

Great, very good input, thank you. Anything else? Okay, I think...is there one more slide about our homework? Our next steps and then...or do we want to go ahead and open to public comment?

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

Let's open up Patty and then we can talk about next steps.

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

All right.

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

Lonnie, can you please open the lines?

Public Comment

Lonnie Moore – Meetings Coordinator – Altarum Institute

Most certainly, 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

Thanks, Lonnie. So, Patty I don't know if you want to review our next steps or if you want me to or Margeaux to?

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

...

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

Sorry.

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

Well, let me...so let me ask if my Co-Chair, Donna, has any comments for us before we go into next steps and then Michelle you can take it.

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

Okay.

Donna R. Cryer, JD – Principal – CryerHealth, LLC

I've truly appreciated listening to this robust conversation. Thank you, everyone.

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

Okay, thanks, Donna. All right, Michelle, wrap us up.

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

Yes, so, thank you all for your thorough review of the Playbook so far. So, during our next meeting we will do an overall review of the Playbook we might bring back the feedback that we've heard through our past few meetings as well maybe quickly recap those items as well. So, we'll send out a reminder but the next iteration of the homework will be due on July 14th but be on the lookout for the reminder e-mail for you all to complete before our next meeting.

And also to note we're just working through our work plan, as we've mentioned when we started this group you all would be assigned to different tasks as they came up from ONC so we do have additional meetings on the calendar, we may or may not need them depending upon items that are coming out through the pipeline so we'll just keep you all informed and as soon as we know we will let you all know as well. Margeaux or Lana any other additional comments?

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

This is Margeaux no additional comments from me, but Lana any?

Lana Moriarty, MPH – Director for Consumer e-Health, Office of Programs & Engagement – Office of the National Coordinator for Health Information Technology

No, this is Lana, just wanted to thank the Task Force members again for such a thorough review, we really appreciate it and look forward to talking with you again on Monday.

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

Okay, well it looks like we have no public comment. So, again, thank you everyone and enjoy the rest of your day. Talk to you soon.

Kevin Fowler – Consultant – Kidney Health Initiative

Thank you.

Carolyn Kerrigan, MSc, MD – Professor of Surgery – Dartmouth-Hitchcock Medical Center

Thank you.

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

Thank you.

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

Thanks, again.

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

Thank you.

W

Bye-bye.

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

Bye.