

**HIT Policy Committee
Consumer Empowerment Workgroup
Transcript
September 26, 2013**

Presentation

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Good morning, everyone. This is Michelle Consolazio with the Office of the National Coordinator. This is a meeting of the Health IT Policy Committee's Consumer Empowerment Workgroup. This is a public call and there will be time for public comment at the end of the call.

As a reminder, this call is being transcribed and recorded, so please state your name before speaking.

I'll now take roll. Christine Bechtel?

Christine Bechtel – National Partnership for Women & Families

Good morning.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Good morning. Um, I haven't said this roll call very often. So if I say your name wrong, if you could please correct me. Korey Capozza?

Korey Capozza – HealthInsight

Present.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

James Cartreine?

James Cartreine – Brigham and Women's Hospital/Harvard Medical School

Present. It's Cartreine.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Thank you. Scott Fannin? Leslie Kelly Hall? Katherine Kim? Sarah Krug? Rita Kuka, Kufaka?

Rita Kukafka – Columbia University

Kukafka. Good morning.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Good morning. Patricia MacTaggart?

Patricia MacTaggart – George Washington University

Good morning.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Beth Morrow? Jan Oldenburg?

Jan Oldenburg – Aetna

I'm here. Good morning.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Good morning, Jan. Casey Quinlan? Clarke Ross?

Clarke Ross – Consortium for Citizens with Disabilities

I'm here. Good morning.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Mark – good morning. Mark Savage?

Mark Savage – Consumers Union

Here. Good morning.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Alicia Stanley? MaryAnne Sterling?

MaryAnne Sterling – Sterling Health IT Consulting, LLC

I'm here. Good morning.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Good morning. Ann Waldo? Ryan Witt? Terry Adirim?

Terry Adirim – Health Resources and Services Administration

Yeah. Hi. Here. It's Adirim.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Thank you *[laughter]*.

Terry Adirim – Health Resources and Services Administration

It's okay.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Cynthia Baur? Bradford Hesse? Hess?

Bradford Hesse – National Institutes of Health

Hesse and I'm here.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Hesse, *[laughter]*. Uh, Kim Nazi?

Kim Nazi – Veterans Health Administration

I'm here. Thank you.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Danielle Tarino?

Danielle Tarino – Substance Abuse and Mental Health Services Administration

Here.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Teresa Zayas Caban?

Teresa Zayas Caban – AHRQ

Good morning.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Good morning. And are there any ONC staff members on the line?

Mary Jo Deering – Office of the National Coordinator

Mary Jo Deering.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Good morning, Mary Jo. And I'll pass it back to you, Christine.

Christine Bechtel – National Partnership for Women & Families

Great. Well, thank you everybody for joining, um, again today. We are going to continue our discussion on patient-generated health data.

As you recall, um, on the last call, we summarized some key findings from the listening session that we held and we presented some draft recommendations. We had a lot of, um, great suggestions with respect to those recommendations. So what we are gonna do today, um, is to, um, present a revised set of those recommendations to you that we believe, um, reflects your input from the last call. Um, and we will go through, um, a discussion to make sure that we're all comfortable with them and that we like them.

The next step will be to present them to a joint meeting that we are going to have with the Consumer Technology Workgroup, because, as you know, we have a couple of asks, um, uh, into them. Um, and so we're gonna present them to that group and we're gonna hear about their work. And, um, then we'll present them also to the Health IT Policy Committee. So it's, it's important that we, um, really focus on, on getting those draft recommendations right, um, today.

So any questions, um, before I jump in?

Okay. Can we have the next couple of slides? I think we're sort of – there we go. So, um, that – so I just reviewed the agenda. Good to go. Keep going. Um, one more. All right.

So, um, what you'll see on your screen – I'm not gonna go through everything, because you've already seen all of this. The changes, um, or additions that we've made are going to be reflected in red font.

Um, but as you recall, we start with a series of kind of key takeaways, first, including the definition of patient-generated health data and how they are different from data generated in clinical settings. Um, and then, um, so that's this slide.

On the next slide, um, we also found that patient-generated health data is definitely not new, um, and that there are lots of mechanisms available for incorporating patient-generated health data. As you guys recall, the ones that we heard most commonly in the listening session were secure messaging, stir, um, surveys and, um, biometric and device data.

We also heard, very importantly, that providers need to be able to do four things with respect to patient-generated data. They need to be able to receive it, review it, respond to it or acknowledge it, um, and record it.

Next slide. Okay. So, as you guys, uh, recall background, um, um, MU Stage 3 sets up some of those capabilities, particularly to receive and record. The focus there, the primary mechanism is a menu item, um, that we'll talk a little bit about, which is the, um, structured or semi-structured surveys. And we're gonna talk about giving some potential feedback to, to that group.

Um, and on the next slide – okay. We talk – actually, we also talked about the importance of providers establishing policies and procedures ahead of time to, to set expectations and know how to appropriately handle patient-generated health data *[clears throat]*.

We found that, um, the liability issue that is often present with PGHD is really reduced, um, or is sometimes eliminated if it is a predetermined and, you know, largely provider determined type of patient-generated health data. So they're asking for it meaning they're gonna put the workflow in place to know how to handle it as opposed to getting a flood of say, you know, device data or other unsolicited, um, types of data.

Um, so we also heard from a great speaker who talked about HIPAA, um, establishing some rights around corrections, but acknowledging that providers can go beyond that.

And, at the end of the day, everybody wants the same thing, which is high quality information. We just need to make it easier for both patients and providers.

Next slide. All right. So that – those were sort of the essential, um – that was the essential summary points. I'm gonna jump into the recommendations here, which is really where we want you to weigh in.

Uh, but before we do that, any, um, anything that we are missing? Okay.

So I just realized too that I don't think, um, our – okay, but the red, uh, elements, um, that I described are actually not in there. I have a back-up deck, so I'm gonna grab that so I can highlight those, um, in the, um, recommendations as we go through them *[clears throat]*. So, all right.

So, on the next slide – let's see here. We're, um – as you guys recall, um – sorry, one second here. Okay. Um, we have the original objective from Meaningful Use Stage 3 draft, um, is on your screen now. So the, um, specific measure was, um, that providers would provide the ability to electronically submit patient-generated health information through semi-structured or structured questionnaires and they would do that for more than ten percent of all unique patients seen by the EP during the reporting, um, period. That was the original draft. This group was, um, okay with that. Um, but I'm gonna pause in a minute.

Um, there's been some work to reshape how the recommendations are presented. It's not finalized. Um, but the – and, and the Meaningful Use Workgroup is trying to get to the appropriate level of detail, but there is concern that some objectives are overly specified.

So, on the next slide, you'll see a potential way to approach, um, PGHD, um, in a new sort of format. And we want to pause and get any reaction that you have to this, since our goal here was really to give the Meaningful Use group some feedback about it.

So, as you can see, the former objective that I just mentioned, ten percent of all unique patients during the reporting period, um, have the opportunity to provide patient-generated health data. That's on the left.

Um, and then the functionality, um, goals, um – or I'm sorry – the example is in the middle column, right, which is, again, the same thing. There's a structured or semi-structured questionnaire. It's a menu item.

And then, thirdly, the functionality goals, right, so this is really the point of this whole thing is online access to health information, provide the ability to contribute information to the record including patient-reported outcomes, and patient preferences are recorded and used.

So, I'll pause and ask for, um, comments on the – on, on any of these columns.

Jan Oldenburg – Aetna

Um, this is Jan Oldenburg, and, eh, um, the way it's framed is really very narrow. And it worries me that, um, it excludes any ability for patients to upload data from tracking devices, which is the most, um, me – you know, it's one of the ways in which people can track their data in a way that's not intrusive into family life. So creating questionnaires requires them to do something else after they track the information. Whereas, if they can load, upload it from, um, the, the device that they use to actually track it, it's going to be more effective for them and they're more likely to do it. So, eh, I worry that we're cutting off one of the things that consumers are actually most likely to use in favor of something that is easiest for systems to implement.

Christine Bechtel – National Partnership for Women & Families

So that's a great question. And you've anticipated some later slides. That was definitely a key theme, um, from the listening session and we talked a lot about that.

Um, the Policy Committee has been told by the Standards Committee, though, that it's, um – eh, previously, um, that it was not possible at this time to bring consumer device data into meaningful use, because there's a lot of work that needs to be done in the sense of you, you don't want every single piece of data from the device to live in the EHR. You want an aggregated set of data that is a summary of trending and things like that.

So, as you may recall, we have already asked the Consumer Technology Workgroup to give us some advice on whether or not we could use cloud technology or whether there could be another way to get device data into Stage 3. And that, um – you're gonna hear about that a little bit later, but that's gonna actually be the focus of the, um, joint meeting that we will have in October with the Technology Workgroup.

So we haven't given up on that. But, right now, in the absence of that work being completed, we're not ready to say that it should be in. So we have sort of a placeholder for that. Okay?

Rita Kukafka – Columbia University

This, this is a – it's Rita Kukafka. I have a question just for clarification. Is, is the – you might not know what the intent is, so it's an intent question. But is the intent of this for patients to enter data that would be used in their health care, in which case, if it goes into a PHR, it might never be brought into the way health care is delivered and practiced. Is it –

Rita Kukafka – Columbia University

– in other words, it has – yeah.

Christine Bechtel – National Partnership for Women & Families

So, no, the intent is – I, I suppose a copy could go to their PHR. I'm not sure. But the intent is for the provider to be the one who is asking for the data and thus incorporating it into their EHR. So you can see in the middle column we give some e.g.'s here, like a screening questionnaire or maybe even an intake form, risk assessment, a functional status survey.

Rita Kukafka – Columbia University

No, I, I understand. Yeah, I understand that part. But it doesn't make clear to me that this wouldn't be something that patients would be delivering to their PHR and never make way into the EHR or actual – it'd be used by a provider in the way that you're suggesting.

Christine Bechtel – National Partnership for Women & Families

Well, because it's the – I, I – so I think we're assuming that it is – this is the Meaningful Use Program, which only governs the EHRs. And so the EHR, there's a set of certification criteria that go along with this for EHRs.

Rita Kukafka – Columbia University

Right.

Christine Bechtel – National Partnership for Women & Families

And it's the provider through their EHR that's asking for the data and the data flows into their EHR.

Rita Kukafka – Columbia University

Okay. 'Cause that's not –

Christine Bechtel – National Partnership for Women & Families

Not to the consumer PHR.

Rita Kukafka – Columbia University

That's not input. So it is the, the EHR, not the PHR, 'cause it's not stated here.

Christine Bechtel – National Partnership for Women & Families

Yeah.

Rita Kukafka – Columbia University

Uh-huh.

Christine Bechtel – National Partnership for Women & Families

Right. It's assumed, because meaningful use only governs EHRs. It has – doesn't govern PHRs.

Beth Morrow – Children's Partnership

So, Christine, this is Beth. Um [clears throat], it, it is confusing to me why if, um, it's meant to give providers the, the option that makes the most sense for them to request data. So does the exclusion of the device data mean that there is no provider that is currently really utilizing that element of technology?

Christine Bechtel – National Partnership for Women & Families

No.

Beth Morrow – Children's Partnership

No.

Christine Bechtel – National Partnership for Women & Families

Not necessarily, Beth. It's just that – remember that meaningful use doesn't dictate – it's a floor. It doesn't dictate all of the things that a provider is maximally allowed to do with their EHR. So I think there may be some that have interfaced their EHR somehow with device data. Um, but, but they're – it's not typically done in a standardized fashion.

And so what we tried to do through the Meaningful Use Program is leverage the certification process that creates a common set of standards and capabilities for any EHR that's being used for meaningful use, right, um, to have the – that, that capability.

So, on – in October, we're gonna hear more from the Technology Workgroup about how that might be able – how that might, um, be possible through Meaningful Use Certified EHRs.

Beth Morrow – Children's Partnership

I see. So it's not yet standardized, but – because I would think we want to reward providers that are choosing to, you know, bring that data in and use it where, where it's being done if we can.

Christine Bechtel – National Partnership for Women & Families

Yes. Um –

Beth Morrow – Children's Partnership

Okay.

Christine Bechtel – National Partnership for Women & Families

– and, uh, and I agree with that. Um, so I – the challenge is that, that the way Meaningful Use Program is structured is a set of requirements.

Beth Morrow – Children's Partnership

Yeah.

Christine Bechtel – National Partnership for Women & Families

And so those requirements need to have standards with them. So we will hear in October about those availability of standards. And I think you should kind of hold that idea of, you know, how do we give credit for that and think about that in the meeting with the standards folks, who should be able to help us think that through.

Beth Morrow – Children's Partnership

Okay.

Christine Bechtel – National Partnership for Women & Families

Okay? So, um, I, I want to point out too, I think it was Rita's question, um, Rita, in that middle column, you were talking about you were worried about the EHR context.

Rita Kukafka – Columbia University

Yes.

Christine Bechtel – National Partnership for Women & Families

Where it says using CEHRT, that is Certified EHR Technology.

Rita Kukafka – Columbia University

Okay.

Christine Bechtel – National Partnership for Women & Families

So that last sentencing clarifies that for you, and I just realized that.

Rita Kukafka – Columbia University

Yeah. Yeah. Thank you.

Christine Bechtel – National Partnership for Women & Families

Any other, um, thoughts or questions on this?

All right, let's jump into the, um, recommendations, because that, um, may shed some light as well. So, um, oh, okay. Sorry.

There's one more thing in meaningful use, which is to remind you that there is a new, um, item that is provide patients with an easy way to request an amendment to their record online.

Um, Michelle, if you're on, eh, this does not say whether it's menu, core or certification criteria. I think it's certification. I can't recall.

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

It is certification. Is there another slide or did that not get pulled through?

Christine Bechtel – National Partnership for Women & Families

Um, well, no...

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Nope. It's not there. It is certification, though.

Christine Bechtel – National Partnership for Women & Families

Okay. All right. Great. So that's what's gonna create the capability for patients to request an amendment to their record online. Um, and the reason that certification is because you don't want to have – you don't want to force patients to have to amend their record just because the provider needs to meet some minimum. So it's a certification criteria meaning the function will be available to all patients, um, and then, and, um, and it, and it'll be made available in some sort of an easier and obvious way probably through a portal for example.

All right, next slide.

Scott Fannin – Greenway Medical Technologies

Excuse me. Can you hear me now?

Christine Bechtel – National Partnership for Women & Families

Yep.

Scott Fannin – Greenway Medical Technologies

Hi, this is Scott Fannin. Sorry. I had a question a couple slides ago and I, I had some technical difficulties there getting on the phone.

Christine Bechtel – National Partnership for Women & Families

No problem.

Scott Fannin – Greenway Medical Technologies

Uh, can you back to the slide on the, on the sh, on the – we were looking at the structured, uh, forms. I have a question about the struc –

Christine Bechtel – National Partnership for Women & Families

Yeah. So...

Scott Fannin – Greenway Medical Technologies

So is there anything – yeah, thank you. Is there anything on here that, that talks about, um, vocabulary or standardized data sets, um, or is that just left out there, uh, just structured or semi-structured? Does that say anything about, um, how the data is being captured in a discrete way or is that not included in here?

Christine Bechtel – National Partnership for Women & Families

Um, it's, it's – so it's a very good question, Scott. And we, we – in the Meaningful Use Workgroup, which I serve on as well, we had to straddle that, because originally, um – uh, so it turns out the vocabulary for some of these – areas like functional status, uh, there are in fact some standardized vocabularies for, um, how you would measure that. So, in that case, it could be, um, discrete data. That's why we would hope that if you're gonna do a functional status questionnaire, you would use basically structured data. The problem is it's not necessarily standardized data. There's not a standard – you know, a technical, um, IT certified EHR standard for functional status, you know, and how you record the data. So there's a vocabulary, but there's not a standard basically if that makes sense.

Um, so we straddled it to leave some flexibility around structured or semi-structured questionnaires so that they're really looking at getting the data into their system, using, you know, some structure to it minimally, um, so that they can leverage the data later. But the field was simply not prepared for our – a policy that dictated, you know, all of the vocab – what kind of functional status tool you're gonna use or what type of screening questionnaires. It's also almost impossible too, 'cause there's so many different types of providers that are eligible. So that's why we left some flexibility there.

Scott Fannin – Greenway Medical Technologies

Okay. I just – I mean we all know that it's much more useful to have a discrete level –

Christine Bechtel – National Partnership for Women & Families

Yes.

Scott Fannin – Greenway Medical Technologies

– than it is to have like, uh, for example, PDFs come in, um, you know, scanned documents. So that's why I was bringing that up.

Christine Bechtel – National Partnership for Women & Families

Yeah. Yeah. I agree. So then our intent was that it would be structured or at least semi-structured. We just couldn't go completely with discrete data, because the – it – we're just not, you know, standardized enough even on the vocabulary side to do that. So if you think about –

Scott Fannin – Greenway Medical Technologies

Right.

Christine Bechtel – National Partnership for Women & Families

– patient, you know, like patient experience questions, you might want to only grab six off the CAHPS survey and how you gonna – you know, so you can get structured data out of that, but it's not a standardized vote cast so to say.

Scott Fannin – Greenway Medical Technologies

Right. You may not even have the fields in the EHR to, to, to put in –

Christine Bechtel – National Partnership for Women & Families

Yep.

Scott Fannin – Greenway Medical Technologies

– yeah, the answers, so. I, I, I get you. Thanks.

Christine Bechtel – National Partnership for Women & Families

Yeah. Okay. Yeah, no, thanks. And, and just for background for folks, I think what, what we thought was really important and we've talked about this before is this idea that providers begin to get some experience with the real value of patient-generated health data in Stage 3 so that we can advance the field much more in Stage 4, but, but I think there's a case study made to them. Um, and then once they get experience with how valuable it is, they'll want to do more of it and I think be open to, um, more advanced types and more structured and standardized data. So that was the logic.

Katherine Kim – San Francisco State University

Hi, Christine. This is Kathy Kim, and I'm – uh, sorry, I joined in late. And so if this question was already asked, I apologize. But this is gonna be a menu item. Is this the only menu item for patient-generated data or will there be others?

Christine Bechtel – National Partnership for Women & Families

Um, it's a, it's a good question *[laughter]*, and it's, it's not an easy answer. So, um, in one sense, it is sort of the only item that is called patient-generated health data. Um, but there are – and if you guys can maybe mute your phones, we can hear somebody ringing – um, there are some other ways, as we heard in the listening hearing like secure messaging for patient-generated health data to come through.

The challenge we face in trying to, to, um, look at secure messaging as a source of PGHD is how – is that it's very difficult to count. So we have this sort of ten percent of all unique patients have the opportunity to submit information. If you have it in a secured message, you don't know if that is – I'm requesting an appointment or a medication refill or, um, I'm responding to a, you know, flu shot, um, you know, availability that the doc sent out. It just became hard to count. So our idea was to really focus it on surveys to get people started.

So it's not the only mechanism, right, there's secure messaging and there's surveys. Um, but it's the only one we've sort of counted as patient-generated health data, because we needed a way to have a numerator and a denominator. C, CMS needs a numerator and a denominator. Does that answer your question?

Katherine Kim – San Francisco State University

It does. And the reason I ask is I – um, it, if it's a menu item and it's among, you know, you get however many of, of all the menu items that –

Christine Bechtel – National Partnership for Women & Families

Uh-huh.

Katherine Kim – San Francisco State University

– um, if this is the most difficult one for people, it, it'll be the one that they don't do, right?

Christine Bechtel – National Partnership for Women & Families

Right.

Katherine Kim – San Francisco State University

And so that, that it, um, that it – it will not be as powerful in getting people to adopt this and, and the, and the ven, vendors to actually adopt it.

Christine Bechtel – National Partnership for Women & Families

So I wonder, and I know Mary Jo is on the line, I wonder if maybe we should – we're gonna get into the recommendations here, but, um, we should add a recommendation that when Meaningful Use Stage 3 is rolled out, if this element is kept in there, that CMS should provide as much detailed information as possible to make it easy for providers to adopt to this one.

'Cause I'm thinking about, you know, care summaries in Stage 1, which were the least selected menu item. And it was not because they were necessarily, you know, super hard, it's because, uh, there was no guidance on what has to go in it, what do you mean by that, you know, all of that stuff.

And so, maybe, we ought to have a recommendation that gets to that point so people don't not select it because they don't understand it.

Mary Jo Deering – Office of the National Coordinator

Christine? This is, this is indeed –

Christine Bechtel – National Partnership for Women & Families

Yeah.

Mary Jo Deering – Office of the National Coordinator

– Mary Jo. And we will have the final report from the technical expert panel that you heard from in July and that you will likely hear from once again. And in that final report, they will actually write up more, um, completely their recommendations about processes and procedures. And ONC, you know, does intend to post that on our web. So there might be a way to, um, link that document to the MU communications.

Christine Bechtel – National Partnership for Women & Families

Yeah. I agree with that. And I think even at a basic level, Mary Jo, just saying what, what this is, why it's useful and some examples of usefulness. We did – you know, there's some of that language here with, e.g., screening questionnaires, intake form, risk assessment. That's gonna help people, but I think we need a little more of that and so that's a good point.

All right. Let's...

Mark Savage – Consumers Union

Christine, it's Mark.

Christine Bechtel – National Partnership for Women & Families

Hi, Mark. How are you?

Mark Savage – Consumers Union

Um, I'm fine. Thanks. I – sorry I was – dialed in on the wrong line, so I have a comment. Are we, are we still on Slide 11?

Christine Bechtel – National Partnership for Women & Families

Uh, yes.

Mark Savage – Consumers Union

Okay. So I, I noticed back earlier that we, we talked about – uh, sort of a key takeaway was that, um, providers should be able to receive, review, respond, record. And I wondered if that should be listed here on the right as a functionality goal as well.

Christine Bechtel – National Partnership for Women & Families

Yeah. Can you say the first part again, Mark? So what would you list on the func – as a functionality goal?

Mark Savage – Consumers Union

Um, that providers should be able to receive, review –

Christine Bechtel – National Partnership for Women & Families

Oh, yeah.

Mark Savage – Consumers Union

– respond and record. And then I had a –

Christine Bechtel – National Partnership for Women & Families

...one. Yeah.

Mark Savage – Consumers Union

I had a related thought on Slide 7, which I couldn't get in at the time you asked the question, which is – it says there that Stage 3 is set up to receive and record, but I was wondering if with – on the, uh, amendment and correction piece under HIPAA, which is coming up later in your slide deck, if Stage 3 also sets it up for, uh, providers to respond when it's an amendment or a correction.

Christine Bechtel – National Partnership for Women & Families

Yeah. I think that's a great point. So for when you, uh, create the capability for, um, providers to not just receive it, but respond and, and I assume they have the record capability. So, yeah –

Mark Savage – Consumers Union

Right.

Christine Bechtel – National Partnership for Women & Families

– that – those are great points. Thanks, Mark.

Mark Savage – Consumers Union

Yep.

Christine Bechtel – National Partnership for Women & Families

Okay. So, um, let's jump into the recommendations. Next slide, yep, no, keep – one more.

All right. So, I'm gonna flip a little bit back and forth so I can kind of highlight for you guys some of the, um, differences here. So we've refined some of the language in this first one [*clears throat*]. So provider organizations that choose the menu item in Stage 3, they need to establish policies and procedures for handling PGHD, and we've added the phrase in advance of or during implementation of Stage 3, not after the fact, including, but not limited to, the content to be received; the mechanisms by which it's going to be received; how it will be reviewed, acknowledged and recorded, including, but limited not to provenance. Okay. So that's our first recommendation [*clears throat*].

And what I'm gonna do, I think, is I'm gonna take – we've got two slides of recommendations, so we'll go one slide at a time and then have comments in between.

The second recommendation is wholly new based on your guys' feedback last time. Um, it says, in achieving the above, providers should collaborate with patients to ensure that PGHD collection and use works for both parties.

So that was the – uh, and we heard that really from the NHIT group, where they said, you know, when providers and patients work in partnership to figure out, well, what, what health data is the most important and how is the process going to work, that's where we saw the most success.

So, um, we, on Number 3, it's largely the same as it was last time, um, but we've added some things onto the end. So, ONC should work through its own channels and with federal partners to educate providers about the need to establish clear policies and procedures and how best to communicate those to patients and families, including understanding and exercising their rights under HIPAA to amendments and corrections, 'cause that's part of patient-generated health data. So that's going to Mary Jo's point that she just mentioned.

Fourth recommendation and fifth are both new based on our discussion, um, and the input from you guys last month.

So, under Stage 3, um, PGHD will be reflected in the record. All right, it'll be recorded in the record. And HIPAA should govern that data just like it does any other data in the record. But that in the future, we wanted to flag that, that ONC and OCR are gonna need to do some work around, um, consumer apps that collect, um, patient-generated health data and how they use them for secondary purposes. So that's what that recommendation is, um, mentioning.

And then, lastly, on this slide, um, work is also needed in the medium term to examine the policy, workflow and liability issues around unsolicited PGHD. And we're gonna actually talk a little bit about that on the next slide.

But before we do, any comments or reactions to what is here or any changes?

Katherine Kim – San Francisco State University

Um, under four, it says just consumer apps. I don't know if it's appropriate to put consumer devices.

Christine Bechtel – National Partnership for Women & Families

Great idea. Yes. Devices and apps.

Jan Oldenburg – Aetna

And under one, uh, does it make any sense – this is Jan Oldenburg – um, does it make any sense to also note that, um, that, um, handling the export of such data is important as well, so provenance upon export not just upon import?

Christine Bechtel – National Partnership for Women & Families

So, okay. So, meaning if the provider was going to share the patient-generated health data for treatment, payment or operations that it should be sourced as such. Is that what you're saying?

Jan Oldenburg – Aetna

Exactly.

Christine Bechtel – National Partnership for Women & Families

Great. We can add that.

Other thoughts?

Rita Kukafka – Columbia University

Hi. It's Rita Kukafka. So I'm not sure if this needs to be mentioned, but in terms of communicating to patients and families, I wonder if we want to have some language about health disparities in there, um, communicate both to patients and families and, you know, just to address that issue somewhere.

Christine Bechtel – National Partnership for Women & Families

So, perhaps, to say communicate, um, to patients and families at the appropriate literacy and cultural context.

Rita Kukafka – Columbia University

Yes. Uh-huh.

Christine Bechtel – National Partnership for Women & Families

Okay.

Great. All right. Any, um, any other additions, changes or thoughts or questions on these recommendations?

Mark Savage – Consumers Union

So this is Mark. Actually, at – to that last point, that would go in at several places, right? It would so –

Christine Bechtel – National Partnership for Women & Families

Uh-huh.

Mark Savage – Consumers Union

– um, both when we were asking ONC to reach out, uh, to educate, it would go there. When we're, when we're talking about providers working with patients, it would also go there. There may be some other places as well.

Christine Bechtel – National Partnership for Women & Families

So mostly the – in the patient-facing components, Mark?

Mark Savage – Consumers Union

Right. Right.

Christine Bechtel – National Partnership for Women & Families

Okay. Yeah. We can look for those.

All right. Let's go to the next slide.

All right. So here we have, um, all new from – based on our conversation last month.

So first is direct e-mail addresses should be made available to patients in order to open up more options for efficient and effective collection of PGHD whether that's now or in the future.

Um, Meaningful Use Stage 3 should address the capacity for EHRs to accept amendments and corrections, which it already does. I'm almost inclined to just say we support what it's doing.

Um, so, Number 8, we should gain experience in Stage 3 with patient-generated health data so that in future stages we can explore whether secure messaging content has the capacity to be used as a mechanism to ingest PGHD. I probably would say solicit – ah, actually, I think I would probably change that to receive, you know, and facilitate the review and recording of PGHD.

And then, finally, um, we need to do some additional work, therefore, how to summarize and aggregate biometric and device data to show trends to providers. Um, and we're actually going to do that, um, uh, as I mentioned, next month.

So, um, I'll pause there and see if there are any, um, comments.

Katherine Kim – San Francisco State University

Yeah. This is Kathy Kim. On Number 6, um, uh, to make sure that there, that the – there is uh, uh – what do I want to say? That there's – the direct, uh, addresses are able to talk to each other. That when – whether you get a, you know, direct address from one HISP or another that they're able to actually communicate to each other and that's an issue with the provider direct addresses now. So that pa –

Christine Bechtel – National Partnership for Women & Families

Okay.

Katherine Kim – San Francisco State University

Yeah. So patients don't have to have multiple direct addresses depending on which provider organization they're with.

Christine Bechtel – National Partnership for Women & Families

So how would you ... that? Like do we need to say they should have one direct address or interoperable or how would – what, what would the language be there?

Katherine Kim – San Francisco State University

Uh, yeah, I think interoperable direct addresses.

Christine Bechtel – National Partnership for Women & Families

Okay. Thank you.

Female

Uh, this –

Scott Fannin – Greenway Medical Technologies

Hi, this is Scott. Also on Number 6 as well, uh, what, what are the – what's the thinking on this one as far as how pa – how we expect patients to manage this? The whole idea of a direct address to patients is a completely foreign concept, of course. Um, how would they manage it? And how would – you know, kind of – I'm just curious about this particular one how we really anticipate this is gonna be implemented.

Christine Bechtel – National Partnership for Women & Families

Um, Mary Jo, are you able to speak to that? I know there's a lot of work happening right now. I know Microsoft is already issuing direct addresses to patients. Um, and I know –

Mary Jo Deering – Office of the National Coordinator

Right.

Christine Bechtel – National Partnership for Women & Families

– ONC has facilitated a lot of work on it, but I'm not sure that I could speak to it.

Mary Jo Deering – Office of the National Coordinator

Well, I, I, I think that, basically, you've, you've, you've captured it that there is a lot of, of energy and activity, um, underway to promote, uh, the use of direct, uh, specifically associated with Blue Button. And so as various vendors, uh, and various, um, providers or organizations, uh, begin to adopt, uh, and implement, uh, Blue Button, then, you know, that will stimulate the requirement to have direct addresses. So there is an awful lot of, of energy behind, you know, promoting and extending this.

So the thinking is that, um, by the time and, you know, MU3, you know, um, is, um, um, uh, you know, be, becomes, uh, comes into law, um, that, uh, there would in fact be at least some installed base so to speak.

Christine Bechtel – National Partnership for Women & Families

Right. And, Scott, we can follow up more offline with that.

Mark Savage – Consumers Union

Christine, this is Mark.

Christine Bechtel – National Partnership for Women & Families

Uh-huh. Hi, Mark.

Mark Savage – Consumers Union

On a, on Number 8, um, we, we might want to put in a, a placeholder for exploring whether other mechanisms might also serve as a way to ingest patient-generated health data. I seem to recall a hearing by the Consumer Technology Workgroup that was exploring, um – if, if I'm remembering correctly – how CDA headers could be used to, to pull in information from, from, uh, patients and caregivers.

Christine Bechtel – National Partnership for Women & Families

Okay.

Mark Savage – Consumers Union

Uh, I may not be remembering that completely correctly, but the, the more general point is if – eh, since we're looking at, at the future experience to, to, uh, not just mention one possibility –

Christine Bechtel – National Partnership for Women & Families

Yeah.

Mark Savage – Consumers Union

– but to be open to several.

Christine Bechtel – National Partnership for Women & Families

That's a great idea. So we'll do such as blah, blah, blah and others. Yeah. That's great. Thank you.

Mark Savage – Consumers Union

Yeah.

Korey Capozza – HealthInsight

Hi, hi –

Jan Oldenburg – Aetna

And when we – when – oh, sorry. Go ahead.

Korey Capozza – HealthInsight

I was gonna say this is, um, Korey Capozza at HealthInsight, I had another, um – unless there's another comment on, uh, Number 8. I wanted to go back to Number 6 and just ask for clarification on what exactly the phrasing “should be made available to patients” means? Um, that's pretty vague and, eh, they're sort of available to patients now, I guess.

Christine Bechtel – National Partnership for Women & Families

Um, that's a good point. That was coming out of somebody had – on the call last month had mentioned that. I'll see if I can go back through my notes. But what would we want to say instead, because you're right that they are available, um, to some, uh, degree today? So, perhaps, what we mean here is direct addresses can, um – direct addresses for patients – oh, boy, I don't know what we're – what we would like to say, 'cause I can't recall who had, um, made that point. Do you have any thoughts, Korey, on a way to improve this?

Korey Capozza – HealthInsight

Well, uh, I'm sorry I missed the last call, so I'm unfamiliar with the discussion. But is the concept that the provider would, um, essentially connect a patient with that e-mail address personally? Or, um, so that they would sort of acquire an e-mail address during a provider visit? I'm just unclear what it means.

Mary Jo Deering – Office of the National Coordinator

Christine, this is Mary Jo. And it does occur to me that, um, given, uh, let's see it was, uh, Kathy's, uh, point about the need for interoperability and that you wouldn't want, um, each provider issuing, you know, a, a separate, you know, direct address to patients. It could well be that, um, uh, that there is, mm, at present no clear, um, uh, mechanism for issuing direct addresses that it's ensured are in fact, you know, totally interoperable and that, you know, one address fits all. At least to the – um, I wish we had someone closer to the, um, Blue Button activity on the call. So it could be, um, pending some further, you know, discussions with ONC staff who are familiar with this that you need it to say, um, um, you know, uh, you know, a, a mechanism should be provided for interoperable, dir, e-mail, uh, direct e-mail addresses to be made – to be made available to patients. Um, uh, in other words, that there may need to be, um, uh, a mechanism may yet need to be created to accomplish that.

Christine Bechtel – National Partnership for Women & Families

Yeah.

Korey Capozza – HealthInsight

Something more specific here. I, I think a lot of providers – they wouldn't know what that meant.

Male

Chris –

Patricia MacTaggart – George Washington University

Well, and – Patricia MacTaggart. The other thing is, is this directed at the provider or is this something we want directed at HISP going forward? Is this – I mean it, it really is the underlying question that you guys are dealing with is a lot of HISPs don't involve patients right now and it, it's not embedded. So, um, it may not be something a provider can deal with, uh, and, again, it may just be the timing of not – at Stage 3, that will be embedded, so.

Christine Bechtel – National Partnership for Women & Families

Okay. Thanks. That's, that's good. So we'll do some work on this one for sure.

Mark Savage – Consumers Union

Christine, a question related. Um, I wonder if there's an analog in direct e-mail addresses to what in regular e-mail addresses where you can have multiple addresses all forwarded to us, to a common address from the user's perspective. Um, so that if, if for some reason – I mention it just in case. For some reason, doctors need to have, uh, separate e-mail addresses. But from the patient's perspective, you could still have it seen as a wa, one common e-mail address.

Christine Bechtel – National Partnership for Women & Families

Yeah. Yeah, yeah, yeah. Okay. Well, um, let, let us do some offline work, because I want to make sure nobody has already answered this question.

Mark Savage – Consumers Union

Yep.

Christine Bechtel – National Partnership for Women & Families

So, other, otherwise, we will revise it to focus more on either interoperable direct addresses or, you know, a simple – you know, like a simple, single address or whatever we need to, but we'll focus it on that and potentially looking at, um, whether we need to recommend that there be a clear mechanism for issuing direct addresses that are interoperable.

Jan Oldenburg – Aetna

Um, this is Jan and I'd like to add another note, um, with Item 9. So, with Item 8, we opened it up, um, beyond secure messaging to look at, um, other mechanisms for collecting that data. On Number 9, uh, it strikes me that we probably need to, um, explore what's un – what's needed to summarize and aggregate and correlate, not just by a medical, de, biometric device data, but, um, all of this consumer data. That it's gonna be far more useful if it's not discrete elements, but if they've got a way of looking at trends across all of it.

MaryAnne Sterling – Sterling Health IT Consulting, LLC

Christine, this is MaryAnne Sterling and I wanted to, to just throw in a general comment, um, kind of expanding on, uh, the comments that have been made around, uh, Item Number 6 about direct e-mail addresses and, and patients possibly not understanding this. Overall, I think we may be missing, uh, an, an educational component across the board here. We're kind of assuming, uh, that, that everyone's gonna understand all of this particularly patients and family caregivers and that may not be the case. So I, I would love to see some reference here to actually, uh, you know, uh, uh, providers, uh, educating, uh, or somebody [laughter] educating patients and families about patient-generated health data, about direct e-mail addresses and about the implications of all of this.

Christine Bechtel – National Partnership for Women & Families

Yeah. So can we go back one slide? So, MaryAnne, on – the Number 3 was designed to do just that. If you have language changes to send to strengthen it, let's definitely do that.

Um, on the last call, we talked about the fact that it made more sense for the providers to be doing the ones educating patients and families about it, because it was then contextualized to their care and targeted to the people who were being asked to engage in that way as opposed to be a big public education campaign, which is not gonna apply to a lot of people. It's a, you know, pretty weird term anyway. So we, we decided to kind of focus on working through the providers to establish the clear policies, procedures around PGHD and then to communicate those to patients and families including understanding their rights to amendments.

So if you want to suggest some additions and strengthening that, that – those changes would be welcome.

MaryAnne Sterling – Sterling Health IT Consulting, LLC

Definitely. I'll, I'll take a stab at that, Christine. Thanks.

Christine Bechtel – National Partnership for Women & Families

Great. Thank you.

Mark Savage – Consumers Union

Christine, this is, this is Mark. I, I, uh, agree with the thought on the last call that, um, providers would be an important source of education. It still may not be mutually exclusive. Uh, there still may be room for some general, uh, work by ONC to educate patients as a, as a general rule.

Christine Bechtel – National Partnership for Women & Families

Okay.

Clarke Ross – Consortium for Citizens with Disabilities

Christine, uh, this is Clarke.

Christine Bechtel – National Partnership for Women & Families

Hi, Clarke.

Clarke Ross – Consortium for Citizens with Disabilities

Hello. I have a, um, tenth item, but it relates to two, seven and eight, um, and it's something we've discussed before, so let me throw it out. Um, address the capacity to include non-medical community-based organization contacts, services and supports as reported by the consumer patient.

Christine Bechtel – National Partnership for Women & Families

Say it again, Clarke.

Clarke Ross – Consortium for Citizens with Disabilities

Address the capacity to include non-medical community-based organization contacts, services and supports as reported by the consumer patient.

Christine Bechtel – National Partnership for Women & Families

What do you mean by that?

Clarke Ross – Consortium for Citizens with Disabilities

I mean, uh, people with disabilities whose daily support is, uh, Medicaid-financed, waiver, home and community-based services and, um, uh, uh, currently, uh, there's total segregation in many states and communities between the health care delivery system and, uh, the ongoing daily, uh, community living support frequently managed by different health plans. And this is merely opening the door, uh, to allow – and, and we've done this when we worked on, uh, coordinated planning, uh, open the door to allow the consumer patient to enter into his own, her own record that, um, I rely on the Easter Seals and the Easter Seals provides the following supports to me. And the contact at the Easter Seals is Mary Smith. Um, so that's my intent is to, uh, open the door for the possibility of integrated – uh, completely integrated, uh, in one place, um, identification of service supports, uh, that the individual requires.

Christine Bechtel – National Partnership for Women & Families

So in the case of patient-generated health data, are you suggesting that – well, I think there's two things. One is, um, and I think they're separate in my mind, but maybe you'll correct me here. One would be a place where it's identified in the record that these are the following community supports that I use or that I need, which is different in that I mean it, it could be one type of patient-generated health data in, in the sense of like if you sent a survey to your patients they could respond with that. Is that what you mean?

Clarke Ross – Consortium for Citizens with Disabilities

Yes. I'm, I'm – mm, my intent is down the road to integrate the non-medical community base supports into, um, the integrated health record and eventually the health record being integrated into the community support records. So this would be the patient-generated, consumer-generated and the recommendation is merely to address the capacity, uh, not pushing the envelope too much, but opening the door so the issue is addressed.

Christine Bechtel – National Partnership for Women & Families

So it's really addressing the capacity to include in the EHR patient-generated health data with respect to the non-medical community-based organizations contact, services and supports needed by the patient. Is that right?

Clarke Ross – Consortium for Citizens with Disabilities

Yes. That's perfect. Thank you.

Christine Bechtel – National Partnership for Women & Families

Okay. So I think given that is one type of patient-generated health data, my concern is if you call out a specific type in the recommendations, you're gonna have to call out a lot of other types. Um, and so I'm wondering if what you'd be comfortable with if we could – um, I could take it to the meaningful use group and see if the criteria for meaningful use where we talk about survey – you know, you know, structured and semi-structured surveys and we have that kind of e.g. screening questionnaires, um, functional status in that list, we might include some shorter version of community-based supports needed by the patient. Would you be comfortable with that, Clarke?

Clarke Ross – Consortium for Citizens with Disabilities

Whatever, whatever you can get accepted. Um, keep in mind that 7 million of the billion people who are duly eligible for Medicaid and Medicare are non-elderly, severely disabled folks. That's who I'm talking about.

Christine Bechtel – National Partnership for Women & Families

Yeah.

Clarke Ross – Consortium for Citizens with Disabilities

These millions of severely disabled folks who rely on community-based organizations for their daily support. And just promotion of the integration and coordination among the traditional health care providers and those supports. So any language –

Christine Bechtel – National Partnership for Women & Families

Okay.

Clarke Ross – Consortium for Citizens with Disabilities

– is acceptable that keeps the door open for this discussion, I'm fine with.

Christine Bechtel – National Partnership for Women & Families

Okay. Great. Thanks, Clarke. That's helpful.

Mark Savage – Consumers Union

And, Christine, this is – uh, we've heard about this in, in other contexts as well like foster care, so Clarke's point actually, eek, reaches even broader millions *[laughter]*.

Christine Bechtel – National Partnership for Women & Families

Yeah. Okay. Great.

Um, all right, any other – um, we've got about eight minutes left, so any other comments on the recommendations? And we've got about one slide after this, I think, one or two slides.

Mark Savage – Consumers Union

I had one question, Christine. Is the, the – on Number 7, about amendments and corrections, is that going to be a, a core requirement or a menu requirement? Do you know?

Christine Bechtel – National Partnership for Women & Families

So, uh, um, the, um, amendments piece?

Mark Savage – Consumers Union

Yes.

Christine Bechtel – National Partnership for Women & Families

It's a certification requirement. Um –

Mark Savage – Consumers Union

Okay.

Christine Bechtel – National Partnership for Women & Families

– and the reason it is because even if you had it as a menu, um, and you, you would have to structure it in a way that you would have to force like some percentage of your patients to amend their records, and that doesn't make any sense.

Mark Savage – Consumers Union

Okay.

Christine Bechtel – National Partnership for Women & Families

So what we've done is create the capacity in an obvious way for the patient to be able to go, oh, yeah, that's wrong. Let me flag it.

Mark Savage – Consumers Union

Okay. Well, just the observation that the, the accuracy and integrity of data is, is one of the biggest things of concern to people who are do – running HIEs. So, maybe, certification is all that's needed to, uh, to, to, uh, accomplish that. But if you think something else needs to be said, I just mention it.

Christine Bechtel – National Partnership for Women & Families

Okay. Thank you.

All right, any other comments?

Okay. All right. So, as I mentioned, on the next slide, you'll see that we, um, have some requests into the Standards Committee. So we're asking the Consumer Technology Workgroup to examine standards and the market regarding the feasibility of including device data in MU Stage 3.

Um, we're also asking them to make sure that that functionality is, um, included in meaningful use for all of the capacities we need for PGHD, not just receipt, but also acknowledgement, reviewing and recording. We just want to double-check that we have the technical functions built in for those areas.

Um, and then we've asked them to identify any necessary standards that are needed to support patient-generated health data, um, including for biometric and device data, um, for – in summary form.

So, Michelle or Mary Jo, our meeting to talk about and review some draft recommendations in these three areas, um, uh, is in October. We're going to do a joint meeting with the Technology Workgroup. Can you remind me the dates and the times?

Mary Jo Deering – Office of the National Coordinator

It's October 22nd, I believe, Michelle. And I believe it is 10:00 to 12:00 noon.

Christine Bechtel – National Partnership for Women & Families

Yeah.

Mary Jo Deering – Office of the National Coordinator

Let me double-check.

Christine Bechtel – National Partnership for Women & Families

Great. That sounds right. Okay. So, please, mark your calendar for 10:00 to 12:00 Eastern on October 22nd for a joint meeting, um, uh, with the workgroup. And, um, we will hear a lot more about the technical side of the policy recommendations we've just made. Um, and we will, um, reconvene at that time. So any other, um, closing comments or remarks before we go to public comment?

Mark Savage – Consumers Union

Quick question, Christine, on the items to the Consumer Technology Workgroup. Will that include anything on the language and literacy comment made earlier on this call to make sure that those standards are in place?

Christine Bechtel – National Partnership for Women & Families

Um, I think the comment earlier on this call as I understood it was about communicating the policies and expectations to patients in the appropriate literacy and cultural context. It wasn't about the technical standards for PGHD, because the universe of potential PGHD in the way that meaningful use is constructed is so large.

Christine Bechtel – National Partnership for Women & Families

So we did not ask them that. Um –

Mark Savage – Consumers Union

Okay.

Christine Bechtel – National Partnership for Women & Families

– but, you know, we could certainly follow up. It's we – uh, but we need to – you know, we can raise that, um, with them in October. We would just need to know that the universe of, you know, options there is, is a big one. So let's, you know, let's raise it and see what they say.

Mark Savage – Consumers Union

Okay. Did – is it something to raise at that meeting or to raise in advance of that meeting in case they have some quick answers at that meeting?

Mary Jo Deering – Office of the National Coordinator

Uh, this is Mary Jo, and I, I'm sort of helping that workgroup. I guess I'm not quite understanding what technical or standards-based work, um, might be available with regard to health literacy.

Mark Savage – Consumers Union

I, I've heard some people say on some calls that, that we don't have – uh, we, we don't have technology available to adjust for, for different literacies among patient populations. And I've heard people say it's more or less possible to, to, uh, adjust for different languages that people are reading. Um, I've also ... tended to hear that people say we've got that. We've got – we've done a lot of work. There's actually mechanisms in place that we can use. I'm just raising it as a general question.

Mary Jo Deering – Office of the National Coordinator

Yeah. Well, I do know, um, uh, that they, they have not explored that at all. That, that has not come onto, um, their, um, a task list.

Mark Savage – Consumers Union

Okay. So for – Christine, for whatever you think is possible or advisable I just throw that out there.

Christine Bechtel – National Partnership for Women & Families

Great.

Beth Morrow – Children's Partnership

And can we learn more about the, uh, direct interoperability question from this group as well?

Mary Jo Deering – Office of the National Coordinator

Uh, there are people in the group who should be able to answer some of your questions, uh, uh, about that. So, um –

Mary Jo Deering – Office of the National Coordinator

So, so, uh, by all means, I'll make a note that, that you're going to want to look into the question of direct addresses.

Beth Morrow – Children's Partnership

Great.

Christine Bechtel – National Partnership for Women & Families

All right. Okay. So, um, shall we go to public comment?

Public Comment

Michelle Consolazio – Federal Advisory Committee Program Lead – Office of the National Coordinator

Operator, can you please open the lines?

Operator

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

We have no public comments at this time.

Christine Bechtel – National Partnership for Women & Families

All right. Great. Well, thank you, everybody, for your, um, terrific input today. And we will talk to you again on October 22nd. Have a great week.

Mark Savage – Consumers Union

Thank you, Christine.

Female

Bye.

Female

Thanks.

Jan Oldenburg – Aetna

Thank you everyone.

