

**HIT Standards Committee
Consumer Technology Workgroup
Transcript
June 26, 2013**

Presentation

MacKenzie Robertson – Office of the National Coordinator

Thank you. Good afternoon, everybody. This is MacKenzie Robertson in the Office of the National Coordinator for Health IT. This is a meeting of the HIT Standards Committee's Consumer Technology Workgroup. This is a public call, and there is time for public comment on the agenda, and the call is also being recorded, so please identify yourself for the recording. I'll now take the roll call. Leslie Kelly Hall?

Leslie Kelly Hall – Healthwise

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Leslie. Brian Ahier?

Brian Ahier – Gorge Health Connect, Inc.

I'm here.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Brian. Christine Bechtel? Brian Carter?

Brian Carter – Cerner

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Brian. AJ Chen? John Derr?

John Derr – Golden Living, LLC

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Jon. Tonya Dorsey? David Harlow? Art Henderson? Susan Hull?

Susan Hull – Wellspring Consulting

Present.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Susan. Liz Johnson? Tom Jones?

Tom Jones – Tolven Health

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Tom. Mo Kaushal?

Mohit Kaushal – West Health

I'm here.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Mo. Russ Leftwich? Holly Miller? I believe Holly is on as well. Marcia Nizzari? Yair Rajwan? John Ritter?

John Ritter – HL7 EHR Workgroup

John's here. Hi.

MacKenzie Robertson – Office of the National Coordinator

Thanks, John. Anshuman Sharma? Fred Trotter? Kim Nazi?

Kim Nazi – Veterans Health Administration

Yes, I'm here.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Kim. Susan Woods?

Susan Woods – Veterans Health Administration

Here.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Susan. And any ONC staff members on the line, if you could please identify yourself.

Ellen Makar – Office of the National Coordinator

Ellen Makar.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Ellen.

Mary Jo Deering – Office of the National Coordinator

Mary Jo Deering.

MacKenzie Robertson – Office of the National Coordinator

Thanks, Mary Jo. Okay. With that, I'll turn it back over to you, Leslie.

Holly Miller – MedAllies, Inc.

I'm sorry. This is Holly Miller. I'm also on the call.

MacKenzie Robertson – Office of the National Coordinator

Great. Thanks, Holly.

Leslie Kelly Hall – Healthwise

Thanks, MacKenzie. So appreciate all of you that are here today on the call, and wanted to talk about what our goals and objectives will be over the next few sessions. We're really right now still in the formative stages. We're getting a lot of education about what's currently being done in our area. We've heard from the – about the BlueButton initiative. We've gotten a federal government update in past meetings. We've heard about the federal advisory work plans. And today, we'll continue gathering information and education, and we'll hear more about a recent summit at the White House on patient access.

We're also looking in the future to continue education, but also to develop a solid work plan, and today, we'll discuss some tentative and emerging areas of work for the team.

Part of our education information is to learn about what each of us brings to the table, and the skills and the interests that each of us have. If we could go to the next slide, please.

So each of you participated in creating a table of our current activities, related standards, and the priorities each one of us has at this team. And I'd like to today go through that and ask each of you to comment on the gaps that we have listed, if there are any, and also what emerging standards you feel will support the patient engagement that we don't have listed. So be – please be prepared to discuss that, each of you, as we go through this grid. Next slide, please.

This is hard to read, but you'll see that the areas on the top in – highlighted in yellow are the areas where there is currently a good deal of interest and activity by our work team members. That includes the BlueButton and care planning, the consumer vocabulary, long term post acute care, the medication management, patient education, patient-generated health data, and all relating types and the technology associated with it, as well as transitions of care. So those are areas where each of the team members have expressed interest or are currently working.

And this is great news, because this aligns very much with what we've heard on our earlier calls about federal initiatives and current activities and work. So at the – I'd like to hear from the group, each of you talk about are there any gaps represented, and are there emerging standards that are not listed here that you feel will inform our work? And then thirdly, if there's areas of interest that you see are not reflected on this grid, if you could let us know. So let's start with John Derr.

John Derr – Golden Living, LLC

I'm trying to get that thing on my thing. Can you move to the next person, and I'll get –

Leslie Kelly Hall – Healthwise

Oh, sure. Okay. Susan Woods?

Susan Woods – Veterans Health Administration

It's hard to read this, so I'm opening up the slides.

Leslie Kelly Hall – Healthwise

Okay.

Susan Woods – Veterans Health Administration

So I can look at – yeah. It's just hard to read it.

Leslie Kelly Hall – Healthwise

Okay. Are you able to read – to open up your attachment from your email and see it more closely, each of you?

Susan Woods – Veterans Health Administration

Yes. That's what I'm doing ____.

Leslie Kelly Hall – Healthwise

All right. So –

Brian Ahier – Gorge Health Connect, Inc.

Leslie, I'm – this is Brian. Maybe I can start, because I have it on the big giant screen in front of me.

Leslie Kelly Hall – Healthwise

That'd be great. That'd be great, Brian. Thank you.

Brian Ahier – Gorge Health Connect, Inc.

Well, and I just wanted to start off by saying, you know, I'd like to add a couple of columns to my row.

Leslie Kelly Hall – Healthwise

Okay.

Brian Ahier – Gorge Health Connect, Inc.

Because I'm definitely very interested in some other things in here. Open source, patient-generated health data, all types.

Leslie Kelly Hall – Healthwise

Okay.

Brian Ahier – Gorge Health Connect, Inc.

Privacy, and secure messaging. And actually, I wonder if secure messaging is not redundant, because we have DIRECT over –

Leslie Kelly Hall – Healthwise

I think we could probably collapse those two.

[Crosstalk]

Kim Nazi – Veterans Health Administration

Actually, I – this is Kim, and I cautious us against collapsing those two, because I think they can be distinct and have –

Brian Ahier – Gorge Health Connect, Inc.

That's true.

Kim Nazi – Veterans Health Administration

– quite a bit of difference.

Leslie Kelly Hall – Healthwise

Okay.

Brian Ahier – Gorge Health Connect, Inc.

Point taken. So just add me to secure messaging. I guess that would be secure messaging outside of DIRECT.

Leslie Kelly Hall – Healthwise

Okay. So patient-generated health data, open source, privacy, and secure messaging, Brian?

Brian Ahier – Gorge Health Connect, Inc.

Right. And –

Leslie Kelly Hall – Healthwise

Okay. Are there any gaps that you see, in general?

Brian Ahier – Gorge Health Connect, Inc.

Well, I think we've done a pretty good job at capturing the broad spectrum of areas. I – you know, there has – I've been thinking about this as I was going through the meeting materials and thinking, do we really want to – it might be better if we keep it a little more narrowly focused, you know, although we do want to – and I can't think of anything that's not on the list, but we do want to keep aware of emerging standards activities and emerging areas where it'd be appropriate for us to add – I don't have any to add at this point, no.

Leslie Kelly Hall – Healthwise

Okay.

Susan Woods – Veterans Health Administration

This is Sue Woods. I'll just make a few comments. So I think we'll – I think we'll all need a little time to really review this and absorb it and think about it. One way I tend to categorize things is I think about the functionality. So you have specific function – some functionality in there, so things that are available to people, to consumers, things like transactions, like medication refills, or requesting an appointment, or other kinds of functionality would be communication, like receiving reminders, or, you know, through email or text about needing – you know, an appointment being changed, or a medication being – needing renewal.

Other kinds of functionality would be expert care, so secure email. And I agree with Kim wholeheartedly. I think we're blurring the lines between secure email, between patients and care team members and secure messaging, which is now becoming the terminology for connect, and connecting provider to provider. So that means something very different.

So there's functionality components there. On top of that, there are issues related to either development, like standards, and again, I haven't really had time to look at these, certification, things that are related to either development or integration, interoperability, you know, getting the job done, getting the highways built and the tools built.

And then there's sort of issues that transcend all of that, which has to do with usage, usability, value, outcomes. And so we may want to think about – we may want to think about organizing things that way.

Leslie Kelly Hall – Healthwise

So that's great. So I hear maybe three areas. One is really the transactions and functionality. Another is the standards development, certification, interoperability, more of that infrastructure. And then the third is really in issues that transcend all, which would be outcomes – I would imagine privacy and security, for instance, might fit into that. Okay. That sounds great. How about – let's see. John, are you ready?

John Ritter – HL7 EHR Workgroup

Sure. This is John. I've got a couple of categories. Some of them might already be tackled, but let me just give you my list here.

Leslie Kelly Hall – Healthwise

Okay.

John Ritter – HL7 EHR Workgroup

I'll start off by saying that the HL7 personal health record system functional model, which is the standard, went through ballot reconciliation, and we're now getting ready to burn new copies of that standard and put it out for joint ballot at HL7 and ISO. ISO is the International Standards Organization, technical committee 25 – 215, healthcare informatics. So this is a national and international standard that very well may apply to the work that we're doing here, and especially for certification. So that's an update from the standards side of things.

Now another part is we've launched an – at HL7 we've launched an EHR usability workgroup to try to find ways to verify that the EHR systems are usable by the professionals. My suspicion is whatever usability-related functionality can be folded into the EHR system functional model to ensure that EHR systems do what they're supposed to do and are usable by the people that need to use them, those might also apply to the citizens, the consumers. The consumers need to have the ability to purchase and use systems that are certified to be usable. So whatever we do on the EHR side can be applied to the PHR side.

Next, low and middle income country settings. In other words, there needs to be a maturity model-based approach here, because there are different levels of maturity of infrastructure and understanding by the user and ability to communicate with care team members. In other words, it goes from nothing to complete. And so we've got to have a low and middle income country resource capability that takes into account those folks that don't have, you know, the same means of accessing personal health record or consumer-related technology as others might.

Next, I think you already got this in there, mobile health. That's a big field right now, and the mobile health experts are scratching their head and wondering what mobile health really entails. And so there's a mobile health workgroup at HL7 who's trying to tackle that question. They've been at it for about a half year or a year now, and whatever progress they make can and should be applied to the work that we do here.

One category that I thought I spotted as missing from our list here would be public health related stuff. That is, notices from public health. For example, a certain virus is headed your way. Make sure you get a flu shot, you know, before the winter. Something like that. So there's interplay between the consumer and public health that needs to be considered.

Next category might be disaster or an emergency. For example, the local elementary school has a power failure, and a note needs to be sent out to the consumer, that is the parent, to go pick up your kid, because you can't have kids getting hungry or not taking their diabetes medicine or whatever it is. So it could be a health-related concern.

And lastly, communications with the health navigator or the health concierge. These are people who are not the professionals, not the professional caregivers, but stand between the citizen and the professional, who help people remember to do things, or to take pills, or to visit them, or whatever it is. And a communications system needs to be set up in such a way that the citizen has a navigator that helps them that is not quite as expensive as the professional caregiver. And this is also a health related aspect. That's all I have.

Leslie Kelly Hall – Healthwise

Okay. That's great. And then what I will ask the group is to update – we'll take this feedback, we'll update the information and send it back for one more final review. But I'd really like to also note where there are opportunities for people to learn more about any of these topics. So for instance, John mentioned PHR certifications that are going forward for ballot. I'd ask you then, John, to say here's a great opportunity. Here's a upcoming meeting, and here's where people could learn more. So that would be very, very helpful.

John Derr – Golden Living, LLC

And Leslie, this is John Derr. I can comment now. I've got it on my –

Leslie Kelly Hall – Healthwise

Okay. Great.

John Derr – Golden Living, LLC

Well, my – as always, we're a little bit of a hybrid. I'm representing, you know, skilled nursing facilities, home care, assisted living, CCRCs, LTACs, and our patient engagement is kind of different. You – most of you represent people at home, and a home in our case is the people that are living in nursing homes or living in assisted living or CCRC, and then we transfer people home, and also we deal with the loved ones who have people in a nursing home.

So it's very important to us, but it's a little bit different than the rest. And I'm going to comment on my X marks that are on there.

Leslie Kelly Hall – Healthwise

Okay.

MacKenzie Robertson – Office of the National Coordinator

John, this is MacKenzie. I just want to – there seems to be a bit of an echo in the background. If I can please ask everybody to mute their phones. Thanks.

John Derr – Golden Living, LLC

Make sure mine – so the first is the BlueButton. What we're advocating here in the BlueButton, and we just had a big summit on LTPAC HIT, and I'm advocating both the vendors to incorporate the BlueButton into their EMRs, and also for admission, because it would be great for – especially in skilled nursing facilities, for somebody when they come in to get permission to use and put in a BlueButton, and then we would have three years of information right away to start our chronic care care planning.

So BlueButton has sort of been, in the last month or two that I've been talking to other people and giving talks, is sort of a aha, this would really be neat for us to do. So that's the status on that.

Care planning, of course, in the S&I framework, we have the longitudinal care committee, and they're working on care plan for a longitudinal care plan, and the standards that are in for that. And what we're looking for is that both the loved ones and the patients – we have in the nursing homes already somewhat of a – EMRs are all developing under longitudinal care planning. One concern I've had is that when we receive a discharge or a transition of care from a hospital pertaining to a hip implant, that we get a care plan from them just on that specific issue, and we have to convert that. And this happens in home care as well. We have to convert that to a longitudinal chronic care plan, and sometimes when we get people visiting the nursing homes, they want to see just what the care plan was that we got from the hospital, and that is not always germane once you're into a chronic care situation.

Leslie Kelly Hall – Healthwise

So you really – you like – your interests are expanding long – not just in long term post-acute care, but making sure care planning accommodates all the different steps of care – of care, including those in the nursing home and those that are transferring or transmitting – transitioning?

John Derr – Golden Living, LLC

Yeah. We sort of get it, and that's why it's somewhat illogical that we got left out of _____. But we have to convert that to a chronic care longitudinal plan, because the average length of short stay, for just short stay rehabilitation, is 24 days. And of course, for dual eligibles, they're over 100 days. So we have to have a longitudinal plan. And what we're looking for now is alerts and all that, so we can move from the episodic stage to the predictive stage, and then eventually into the preventive stage.

Leslie Kelly Hall – Healthwise

Okay.

John Derr – Golden Living, LLC

And then we hope we send them home. What's happening now is a lot of times they're being sent to assisted living, and – which is gaining more and more – a little bit more acuity, because there's not as many beds in a SNF. So we would like to send people home, and – but the payment system is sort of blocking that, because we would like to get into a patient throughput system, not a census system.

Leslie Kelly Hall – Healthwise

Okay. Super.

John Derr – Golden Living, LLC

So –

Leslie Kelly Hall – Healthwise

Anything else, John?

John Derr – Golden Living, LLC

Just the rest of them – I sort of summarized all of them in that statement.

Leslie Kelly Hall – Healthwise

Okay. Great. Thank you. And Holly Miller?

Holly Miller – MedAllies, Inc.

Yeah. Hi. Thank you for the opportunity to speak to this. I had a couple of comments that I'd like to make. First of all, I really appreciated someone else's comment on the public health and the interface with consumers, because as we collect outbreak data and other information, I think it'll be really important to be able to alert and inform consumers about this information.

The other area that I'd like to touch on that we have listed, but has – has me concerned, is the interface between patient-generated health data, and then how that's managed by the clinical community. So – and I'll just give a quick example, which is something that I recently witnessed that had me concerned. A patient through their linked personal health record had gotten an alert that they were overdue for a test. They actually went into the care facility to schedule that test. Maybe they were there for something else, or maybe they lived nearby. I don't know. But they went in to schedule that test in person. Maybe they were hoping to have the test done that day.

And they were told that despite the fact they'd gotten an alert to the effect that they were overdue for this test, their doctor hadn't ordered it, so it couldn't be scheduled. So to make sure that as we go forward, that there really is some workflow consideration in the implementation of the guidance that we give.

Leslie Kelly Hall – Healthwise

Great.

Holly Miller – MedAllies, Inc.

So those are the things I wanted to touch on that I think are very important.

Leslie Kelly Hall – Healthwise

Thanks, Holly. Let's see. Tom Jones?

Tom Jones – Tolven Health

I have to come off – I have to come off of mute. Did I come off of mute?

Leslie Kelly Hall – Healthwise

You did.

Tom Jones – Tolven Health

Oh, good. Fine. I live in a world where a lot of these things rise to a level of abstraction that doesn't allow for very comfortable splitting. So I tend to be a lumpner. So what I mean by that is many of the things that we've spoken about, I would like to see us step back and rephrase ___ ___ and said, look, the patient/consumer is a caretaker, not just a care receiver. And so every piece of functionality, understanding with any system we have roles and permissions, but with any piece of functionality, we need to say, what is this like for a caregiver? Not just a care receiver.

And it tends to bring a lot of this stuff into high relief, such as standards for privacy, standards for vocabulary, standards for messaging. It ought to be a fairly universal set of standards for the creation and use of health information, let alone its exchange. And anybody these days who thinks they can develop a personal health record without being mindful of the totality of health information exchange is just foolish, because the infrastructure right now for certified clinician health records is the infrastructure for health information exchange. You got to bring stuff in. You got to send it out.

And now we're saying not only do you have to bring stuff in and send it out, it's got to be understandable, comprehensible. That means that we have to stop talking about these highly specific standards for these tests of ours, called patients. Instead, start talking about how we apply standards broadly to all levels of caregivers, doctors, allied healthcare, home care, patients, families, agents. It's going to help us immensely with reducing the size of the grid, or at least allowing the grids to be interlinked, the grids for, as we've just heard, the HL7 specification of PHR. I haven't looked at it yet because I'm scared to, because I don't know how closely it relates to the HL7 specifications for the EHR. I hope they're pretty close, but I worry, because, again, it's a way of continuing to marginalize the patient, and not treat them as a care provider.

So my interest in this area, and let me just say quite candidly, I've been in the open source environment for nearly ten years, and I'm very familiar with how one develops personal health records in open source technology that operate ____ for health information exchange, so that – a lot of the other things I do, I'm stepping down as chairman of the HIMSS HIE committee. I'm on the executive committee for the Clinical Information Modeling Initiative. All of these things prompt me always to look at this abstract level. Look not at all these little columns and grids, but look at the overarching language, we can reach down, bring those things together, relate them to other members of the care team. So that's enough of my preaching for today.

Leslie Kelly Hall – Healthwise

You remind me of a conversation we just had the patient-generated health data team in HL7, asking that patient-generated health data simply be another source of the consolidated CDA, and harmonized at the header level, and not require any sort of separate or distinct data type, but say anyone who's on the care team, including the patient, has opportunity to correct. So I think that's an interesting way to look at things, and I think warrants further discussion. Kim Nazi?

Kim Nazi – Veterans Health Administration

Hi. Thank you. I have two comments – well, actually, three comments. One comment is that I feel a little like a kid in a candy store in now seeing the full grid. And although we each provided input, I think many of us will want to say, oh, yes, I'm very interested or have expertise in some of these other areas as well. So I hope there's an opportunity to provide that additional input. And –

Leslie Kelly Hall – Healthwise

Absolutely.

Kim Nazi – Veterans Health Administration

Okay. Thanks. And then I think there's two areas that I would put on the table for consideration adding to this. One area would be kind of information sharing. So we know that we've got, you know, various pathways for exchange, but within these systems, there's a very real need to be sure that they offer opportunities for a patient to specify their information sharing preference, and that might be delegation or surrogacy or authorization of let's say patient-generated data to be shared with the healthcare team. So that would be one item you might consider adding to the grid.

Leslie Kelly Hall – Healthwise

Okay.

Kim Nazi – Veterans Health Administration

And then the second that I'm kind of surprised not to see here, but – it may encompass everything, but a specific focus on adoption and endorsement.

Leslie Kelly Hall – Healthwise

All right. Great.

Kim Nazi – Veterans Health Administration

Thank you.

Leslie Kelly Hall – Healthwise

Okay. Thank you. And Brian Carter?

Brian Carter – Cerner

I would generally echo a lot of the sentiments that have been shared. Specific to the work that our organization is doing, definitely the clinical workflow aspects of this, and ensuring that as patient-generated data starts flowing into the clinical setting, that there's workflows that make it easy for the providers to be able to consume and leverage this information. It's going to be hugely important to help drive adoption, because one of the biggest advocates of patients becoming more empowered can be the care team, and getting them on board is going to be really important.

And then specific to that patient-generated data, the thing that concerns us whenever we start thinking about it is really in having a standard way across the ecosystem and systems that'll be sharing data to ensure that we have appropriate provenance of that data that can be preserved, that all systems can understand. Otherwise, we wind up with a pool of data that nobody can really tell where any of that information came from anymore.

Leslie Kelly Hall – Healthwise

Right.

Brian Carter – Cerner

Those are probably the big areas that I would want to make sure that we focus on. And then specific to my areas on the grid, the only thing I don't see myself checked on that I have great interest in is the patient education topic.

Leslie Kelly Hall – Healthwise

Okay. Super. All right. Thank you, Brian. Susan Hull?

Susan Hull – Wellspring Consulting

Good morning, everyone. I'm actually in a noisy airport, so I'm going to be brief.

Leslie Kelly Hall – Healthwise

Okay.

Susan Hull – Wellspring Consulting

I'm not sure I see my material yet on the grid, but I may not be seeing it all. I hope that you've gotten – I've already sent it a couple of times. But I do really echo and applaud the other comments. I'm especially interested in the transparency between the patient and consumer and the provider team, and so thinking about even things like provenance. How do we – how do we ensure that that's available to the care team across the ecosystem, and the patient or family designee across the ecosystem?

The other I guess great concern I have is the proliferation of mobile health apps that are generating more and more kinds of patient-generated health data into the mobile ecosystem, and doing some harmonization work around, you know, kind of harmonizing some standards for ____ of patient-generated data, so we begin to __ ____ similar ways, and other ways, so that as this data becomes more mashed up in the ecosystem, there can be sense-making from the patient and providers.

And then the last thing that I think is a really important construct as we think about shared care planning and shared decision making, it's really the feedback loops that we begin to generate around patients adherence to the care plan, and outcomes, that's either patient-generated data or device-driven data that gets sort of looped back into these cycles of decision making and improvements in the care plan. I think that's an interesting place for us to sort of focus in on.

And so I would – I would like to see us take a look at the shared care planning, shared decision making, you know, outcomes, adherence, or other feedback loops in relationship to each other, and see how we can, you know, make an impact there. And I think the provenance of that kind of data over time is going to be especially important to be able to detect. And I'm going to sign off just due to the noise.

Leslie Kelly Hall – Healthwise

Okay. Thank you.

Susan Hull – Wellspring Consulting

I mean, I'm not signing – I'm going to put myself on mute.

Leslie Kelly Hall – Healthwise

Right.

Susan Hull – Wellspring Consulting

But I'll stay on the call.

Leslie Kelly Hall – Healthwise

No problem. Thank you. Mo? Mo Kaushal, are you there? Okay. All right. Well, thank you very much, all of that's given me – given all of us a good feedback. We'll update this information and send it around one more time. Next slide, please.

Brian Ahier – Gorge Health Connect, Inc.

Oh, sorry. Sorry.

Leslie Kelly Hall – Healthwise

Yes. Yes.

Brian Ahier – Gorge Health Connect, Inc.

This is Brian. Just one thing on this slide, and I don't know if it's appropriate, but it seems to be missing from the scope of our work, and that is consent.

Leslie Kelly Hall – Healthwise

Yeah.

Brian Ahier – Gorge Health Connect, Inc.

And then in particular, granularity of consent and metadata.

Leslie Kelly Hall – Healthwise

Okay.

Brian Ahier – Gorge Health Connect, Inc.

Do you think that that's something that we might want to add?

Leslie Kelly Hall – Healthwise

All right? Thank you. This is –

[Crosstalk]

Fred Trotter – Not Only Dev

And this is Fred Trotter. I would love to comment, too. I'm not sure if I missed my turn or what happened, but –

Leslie Kelly Hall – Healthwise

Oh, I think I didn't hear you. Okay. Go ahead.

Fred Trotter – Not Only Dev

It's no problem. So one of the things that I hear on these calls is kind of a slew of problems that come out. One thing I would like to kind of refocus us on is that we're discussing is protocols, and protocols have a way of solving problems that are not – well, there's the problems that we need to solve regarding the protocols, and then there's problems that protocols solve for us. So, you know, Mint and eBay and Craigslist and Amazon, all of those are mash-ups of the HTTP protocol and the SMTP protocol, but all of those services solve very, very different problems, despite the fact that under – in the underlying way, all they're using is email and web.

So as I'm looking at this grid, right, there's only a few things on here that qualify as a protocol. And when I see – when I say protocol, I mean that it must have a reference implementation in code so that you can actually start somewhere to get it working. It has to have published standards with no licensing issues, so a way for developers to say, I know what the standard is, and I can read it without paying anything. And then it has to have a community of developers that are coalescing around it in order to make the protocol work.

And if you can unstuck those three things for any given protocol, then other people will solve all the really complicated problems down the line, and many of the things that I think we might be considering here don't – are actually problems for protocols to solve, and not actually protocols themselves. So I think what might interesting for this grid, obviously, for my personal line, I'm very interested in DIRECT, and not terribly interested in attitudes, I think, is the – is one that I got put on.

Leslie Kelly Hall – Healthwise

Okay.

Fred Trotter – Not Only Dev

But the protocols that I'm really interested in is actually looking at which ones work and which ones don't. And I – and in many cases, I think it might make sense for us to defer discussion of very particular problems as things that the protocols can solve once they are themselves unstuck. So that's just my two cents. Thanks.

Leslie Kelly Hall – Healthwise

Okay. Thank you. All right. Next slide, please. So one of the things that in forming this workgroup has – we have come to find is that, of course, there was a need for the workgroup, because in many areas of standards development and in many areas of the policy work going on, we see that the patient and consumer is touched on everywhere. So part of this next month, with guidance from ONC and other workgroup leaders, we will be sorting out which group is working on which things.

So to that end, we have opportunities for clarification and very specific outcomes for the work that we project. So for instance, in the consumer area that we want to make sure that patients are part of the national – of the Nationwide Health Information Network, and there's been significant work going on by Dixie Baker and her team. And that group is charged with a lot of the overarching themes and functions for nationwide health exchange, to include consumers.

So we will be working with Dixie's team to determine what portion of that work is for us to do and what portion of that work is for her team to continue. And we have Dixie on the phone, and I'm hoping, Dixie, that you might talk to just very briefly where you think that intersection occurs. And then we've also invited Dixie to present in our next session about some of the emerging standards that her team is recommending to go forward, and its impacts that it will have on consumers. Dixie, are you there? Dixie? Okay. So we'll – we will look forward to her comments and information in the next session.

We also have good overlap that we need to consider in the – in the clinical operations areas. So for instance, consumer vocabularies. How will that be sorted through and used? In policies, things like privacy and security under the privacy and security tiger team. What recommendations will that group have with regard to the patient's digital level of assurance or trust, and how that works and is related to our work? As well as the other teams that we see coming forward with patient engagement principles.

So in the next month, you'll see us have more clarity around who is doing which part of this, and then also making sure that the patient is considered as part of these teams that go forward. So you might receive notices of other team meetings. Myself and Christine Bechtel also might participate in other team meetings, where we see the patient and consumer needs to be included in the deliberation. For instance, this week, the clinical operations workgroup is meeting and has invited both Christine and I to participate in listening into those sessions and offer feedback.

So as we go forward with deciding who's on first, I hope you'll all be patient, and then also share our enthusiasm for this great collaboration between work teams and patient engagement. Next slide.

So I'm going to turn this over to Ellen, and we are very excited to report on a patient access summit that took place at the White House a couple of weeks ago. It was exciting to be there. It was amazing to see how many organizations and individuals are committed to patient engagement and patient access to information, and the high levels of government that support this effort. So we've asked Ellen to come forward and give this group an update on what's going on in that team, and work efforts that we will probably participate in. So Ellen, please go ahead.

Ellen Makar – Office of the National Coordinator

Yep. Thanks, Leslie. So last year – we can go to the next slide. Last year, there was a patient access summit to kick off this work, and what really came out of there is that there was good traction around meaningful use and providers really looking at EHRs and what they needed to do to get them in place. But there was a fear that the patient might be lose in that, and the whole idea of exchange of information and really making sure that that was a focus is what prompted last year's summit.

The major accomplishment that came out of that was that they heard that standards were needed around BlueButton. It wasn't enough just to be able to view and download that information, and then perhaps get to the point where it could be transmitted. It was the creation of something that would be standard so that that could then explode and be used in a variety of different ways. You can go to the next slide.

These were a few of the people that were – presented. It was a large group of diverse stakeholders, patients, data holders, providers, those of us in government, and it was to hash out moving forward what were the next streams of work. You can go to the next page.

The 2013 objectives are listed there, and so because BlueButton guidelines came out in February of 2013, which was a huge success out of the first summit, there was a lot of talk about BlueButton and getting that spread happening. And so folks brainstormed how BlueButton the concept, which is view, download, and transmit, and then BlueButton this standard, or the guidelines, could be used moving ahead. So go to the next slide.

The participants voted on which were the most compelling streams of work. A brainstorming session, they were gathered, and somebody previously had talked about lumping, so they were lumped into categories. So within these work streams, there were a few different ideas that came up, but they've been shrunk down here into one or two bullets, just to kind of give you an idea of what is going to be looked at. And these will be put out publicly, so that other folks will become aware of these streams of work.

But the number one work stream by far was educating consumers about ehealth and getting them involved in creating demand, and creating interest around a media campaign, and getting some momentum. The second work stream that came out was that'll be great, but then we need to make sure that very closely tied to that is those standards and policies that are going to support a consumer being a hub of some of their exchange, and making sure that there were tools and platforms that would work for them. You can go to the next slide.

Work stream three kind of supports all of the other work streams, in that there were some bumps in the road around understanding of HIPAA, or misunderstanding of HIPAA, or misunderstanding about assurance, and making sure that security was in place and was consistent. So that is work stream three, clarification of regulations and policies that will allow people to build upon the platforms.

And then work stream four is we create all this demand. What does that do to providers? Are they going to be ready? Will they be able to implement BlueButton Plus? Once you get to your provider, is there going to be an open door for you as an engaged consumer? You can go to the next slide.

Work stream five is the Automated BlueButton and getting BlueButton to the next level, a technical thing between push and pull, a one to one transaction which is push, and then a more automated, every time that there's a change in your record, that data will flow, as far as BlueButton pull.

Work stream six is around payers and **EOB** content, having a way to look at the data, and making sure that there's a differentiator. All the data has value, but there's a difference between EOB data, or claims data, and then clinical data. So having a format for pulling that information in so that it's consistent is important. And then you can go to the next slide.

One of the other work streams that came out is two of our federal partners, the VA, to a larger extent, CMS, to a good extent, but not to the level of VA, has implemented BlueButton, and is having great success with patients and consumers, and there are a lot of success stories out there around that. So leveraging that work and recruiting more data holders to implement BlueButton is the next big push. So move to the next slide.

The other issue is we have many now BlueButton pledge makers, pledgees, and now it's great to make the pledge, but finding out what exactly have they done is another stream of work, and trying to document that work and spreading the good that's out there, and getting that to be well-known. So I just wanted to know if there was any questions in regards to that, or Leslie, give you a chance to jump in if there was anything I missed. I'm just being mindful of the time.

Leslie Kelly Hall – Healthwise

Any questions?

John Derr – Golden Living, LLC

Leslie, this is John Derr.

Leslie Kelly Hall – Healthwise

Yes? Mm-hmm?

John Derr – Golden Living, LLC

I – since I'm on Medicare, I'm over the age, I have BlueButton, and one thing we don't do enough of is the different apps that put this into readable types of information, and information the vendors can pull. Can you comment on those different apps? Or are we not to promote different apps that put this into readable information?

Leslie Kelly Hall – Healthwise

I think that the best place to get the kind of information is to go to HealthIT.gov, where the organizations who have pledged to the BlueButton have also in so doing provided what they're pledging, and many of those organizations are apps, and organizations have said yes, I commit to this, and yes, we are actively doing that. Some of those came – were invited and came to the White House initiative, like No More Clipboards, I believe, and **Humetrics**, and then larger players in EHR, like Cerner and Epic.

But I think that the best place to find out who's committed is to go to the HealthIT.gov site and look and see who's taken the pledge?

John Derr – Golden Living, LLC

Thank you.

Leslie Kelly Hall – Healthwise

All right. Next slide. So there are emerging areas of work for this team right now, and we hope to have this more solid in the next month. But as you can see, there's both interest, there is huge opportunity in the BlueButton plus. Also, to make sure that we have recommendations around how are we going to provision DIRECT addresses to patients. What do we recommend, being mindful of the workflow that we heard many times over from these team members today, and making sure that patients have easy access.

Other areas that we will see emerging are patient-generated health data, standards for priority areas. We expect to hear from a technical expert panel that was convened by the ONC for – within the National eHealth Collaborative. They will be reporting out into the SACA teams in the next I believe month. Look for more information on that.

We also see that there's a huge opportunity for harmonization, and that was echoed today in the team members, for standards for patient engagement, and also principles, and the consumer vocabulary, are all areas, as well as care planning. So I believe it was Tom that talked about the patient is a team member and is – at that high level, how do we make sure that there's this yin and the yang, when what's good for the provider, there is also a – that yin has a yang. What's good for the patient? How is the patient, the team member, the family member, included in the usability, in the functionality? And then the corresponding standards and protocols that enable that.

So these are areas of emerging work for this team, and I hope that this session is the last where the majority of our time will be spent in education information, and we'll be going forward with continued education in the smaller part, but actual assignments and work effort in the meetings to follow. And I would ask if there's any comments from Ellen or Mary Jo or MacKenzie that you have in this area at all. Okay. Super. With that, I think we can open to public comment, MacKenzie.

Public Comment

MacKenzie Robertson – Office of the National Coordinator

All right. Operator, can you please open the lines for public comment?

Operator

If you're – if you'd like to make a public comment and you're listening via your computer speakers, please dial 1-877-705-2976 and press star 1, or if you're listening via your telephone, you may press star 1 at this time to be entered into the queue. We have no comments at this time.

Leslie Kelly Hall – Healthwise

Super. Well, thank you, everyone. I really appreciate all this great feedback. Look for more information via email, and look forward to meeting again next month. Thank you so much.

MacKenzie Robertson – Office of the National Coordinator

Thanks, everybody.

John Derr – Golden Living, LLC

Thank you. Have a July 4th, happy –

Leslie Kelly Hall – Healthwise

Yeah, yeah. Bye.

John Derr – Golden Living, LLC

Bye.