

# HIT Policy Committee Transcript May 7, 2013

## ATTENDANCE

The following members were in attendance:

- Madhulika Agarwal
- David Bates
- Christine Bechtel
- Christopher Boone
- Neil Calman
- Arthur Davidson
- Connie White Delaney
- Judith Faulkner
- Gayle Harrell
- David Lansky
- Deven McGraw
- Farzad Mostashari
- Robert Tagalicod
- Paul Tang

The following members were absent:

- Richard Chapman
- Patrick Conway
- Paul Egerman
- Thomas Greig
- Charles Kennedy
- Frank Nemeč
- Marc Probst
- Joshua Sharfstein
- Latanya Sweeney

## Presentation

### **MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thank you, good morning everybody, this is MacKenzie Robertson in the Office of the National Coordinator for Health IT. Welcome to the 48<sup>th</sup> meeting of the HIT Policy Committee. Thank you for your patience while we got started this morning. This is a public meeting there are two public comment sessions built into the agenda and the meeting is also being transcribed so please make sure when you speak that you do identify yourself for the transcript. We just had a core member enter the room for those of you on the phone. And for Twitter the hashtag is #hitpolicy. I will now go through the roll call. Farzad Mostashari?

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**  
Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thanks, Farzad. Paul Tang.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thanks, Paul. David Bates?

**David W. Bates, MD, MSc – Brigham & Women’s Hospital & Partners – Senior Vice President for Quality and Safety**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thanks, David. Christine Bechtel will be joining a little bit later. Chris Boone?

**Christopher Boone, FACHE, CPHIMS, PMP – American Heart Association – Director of Outpatient Quality and Health IT**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thanks, Chris. Neil Calman?

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Richard Chapman? Art Davidson?

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thanks, Art. Connie Delaney?

**Connie White Delaney, PhD, RN, FAAN, FACMI – University of Minnesota School of Nursing – Professor & Dean**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thanks, Connie. Paul Egerman? Judy Faulkner?

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thanks, Judy. Gayle Harrell? Charles Kennedy? David Lansky?

**David Lansky, PhD – Pacific Business Group on Health – President & Chief Executive Officer**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks, David. Deven McGraw?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks, Deven. Frank Nemecek? Marc Probst? Josh Sharfstein? Latanya Sweeney? Madhulika Agarwal?

**Madhulika Agarwal – Department of Veterans Affairs**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks. Patrick Conway? Tom Greig? Rob Tagalicod?

**Robert Tagalicod – Centers for Medicare & Medicaid Services – Director, eHealth Standards &  
Services**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act  
Program Lead**

Thanks, Rob. With that I will turn the agenda over to Dr. Mostashari for some opening remarks.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Thank you, I've been reported as having said we're about halfway through the process of computerizing and digitizing America's hospitals and doctor's offices and we're about 5 percent of the way through changing workflows and redesigning care to take advantage of those technologies and I wanted to talk a little bit about what that means to me and talk a little bit about a meeting at the Institute of Medicine yesterday that took on that issue of the redesign of care to take advantage of, not just the financial incentives, but also the infrastructure and tools.

And let me start by telling the story of a really, one of my favorite parts of my week is, every week we have a one-hour call with six clinics affiliated mostly with our beacon communities that are doing an LDL challenge we call it. An effort to take stubbornly resistant LDL control among patients with diabetes rates in six different settings and make a rapid improvement in those measures and as people know, diabetes greatly increases the risk of heart attack and stroke, greatly and yet it is largely those heart attacks and strokes are largely preventable if risk factors like blood pressure and lipid control are addressed.

And yet while the best healthcare systems achieve 85-90 percent rates of blood pressure or lipid control among patients with diabetes in these practices, as in most of America, once you start looking, once you're able to look you realize that you're doing about half of that, 40 or 45 percent of all patients with diabetes, all those who come in the door leave with good LDL control.

And I was speaking with, before we launched this sprint, I was speaking to the medical director for one of these clinics who said "Dr. Mostashari, I hear you have a silver bullet, because we've tried everything" with, you may infer, a bit of skepticism in her voice. "What's your silver bullet Dr. Mostashari, because we've tried everything?" And the approach we're taking is to ask the simple question, if there are 1000 patients with diabetes who come in, 400 go out the other end, where are we losing the 600? Can we answer that question?

So, the first principle is application of data. And to take an outcome measure, which is what people are going to be held accountable for, right? Of all your patients with diabetes how many got the outcome? And to break it down into processes, sub-processes that can be focused on an improved systematically.

So, is the issue that they didn't get the lab drawn? Is the issue that they got labs drawn that showed a high LDL but they were never started on a statin? Is it that they were prescribed a statin but yet their LDL levels are persistently high maybe because they're not taking the medication?

So, the first gate, you know, you have to be this tall to enter, the first gate is can you identify the patients, not just your overall quality measure, which for the first time we're now able to do in many of these practices, but can you actually identify where the process is failing? Where the system is failing? Not where are people failing, right? Because as Brent James said 5% of the problem is people 95% of the problem is systems. And it's systems that help, that let ordinary people do extraordinary things.

So how do we create systems and this – having the window on just, you know, one issue like, helping people with diabetes not have strokes and heart attacks by addressing their lipid control has opened up just wonderful windows into the skills that we're going to need to develop, when I said 5%, we are 5% of the way through the process changes and the redesign of care, those are the skills that we need to learn about.

Skill number one, there are 700 patients first in the one clinic who haven't had a recent LDL test. Well, we've got to get them back in and the clinic sent letters to 700 of those patients, which they can now do because they have electronic health records. They got 50 of them to show up for a weekend clinic. So, that's number one. We've got to be able to much more effectively engage with the patients who, some may call lost to follow-up or need – you can't just wait for them to show up for the visit and we've got to – another group sent an IVR and they got a much better response, they got a 25 percent response rate of people showing back into practice.

I'm sure if we start doing the kind of stuff that marketers have been doing for a decade now and altering the message, figuring out how to couch it we could iteratively drive up higher and higher the ability to get – reengage patients who have been lost. So, that's number one, we've got to be able to engage patients and to use the tools to measure how well we do in engaging them.

Number two, the clinic that was able to successfully bring a lot of patients in, a lot of them left that eight-minute doctor visit that they fought so hard to get without a lab slip, without a prescription. The patient came in, the provider said, how are you? Let's review how you're doing, sounds good and they left again and one of the ideas was, well we should laminate the guidelines and put them in the exam room. And the other insight was let's automate this as much as possible so that we are not relying on the provider making a decision in an eight-minute office visit that gosh this person needs an LDL test.

Let's have it be waiting for them or better yet why don't we tell the patient when we bring them in that you should get – the reason we're calling you back in is because you need an LDL test be sure to get it before you leave or better yet get it before you come so that when you have the visit the provider who is sitting down with you has the results of your lab test in front of them and they can make that decision with you instead of spending one visit just to get the lab ordered and then try to bring you back in once the lab results are available. So that's a new workflow that concept of population health management of lowering the center of gravity, someone called it, in the clinic, new workflows.

The other is the idea of do we really need to individualize every decision is I think the most interesting cultural shift, 45 percent are getting, maybe, individualized treatment, 55 percent are getting nothing. So would protocol-based defaults that say if your LDL is greater than 160 a year ago you're unlikely to have, through lifestyle, reduced it to less than 100.

Let's have a protocol that says the default in these cases should be that we go right to the statin. You could always change it and in fact Brent James said Providers must customize the defaults to the individual person, but at least there is a default there. You've automated as much as possible.

Those are just a few of the kinds of process redesign before the visit and engaging patients in establishing treatment that the tools are there for, increasingly the payment systems are there to reward, but there is a real concern that even if you have the payment and even if you have the tools without the know-how these practices with the tools and with the incentives will not be able to, at least in the short run, accomplish the improvements in quality and cost that we all are rooting for them to accomplish.

So how do we scale this hard-fought knowledge about what works and how to make it work in practice by practice. And we can't just rely on large delivery networks that have done this, know how to do this, have the staff to have dedicated quality control infrastructure. How do we do this not just in 3,000 hospitals but in 180,000 practices? How do we get that to spread I think is going to be probably the most interesting challenge for the next few years.

So, we're halfway through digitizing health and about 5 percent of the way through the redesign of healthcare to take advantage of the payments and the infrastructure in IT and it's going to need new roles for the entire care team including the patient. Onward.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thanks, Farzad. I think I'm going to have an editorial response.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

That's your prerogative.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yeah. How do we make a change? One possibility and it's complimentary to what you said, you said – really talked about our processes in the healthcare delivery system. What about tapping into the 300 million people who are also on the team or bringing them on the team?

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Exactly.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, when the medical director you referred to said "well, we've tried everything," I think she meant, we the healthcare professional team tried everything in our processes. I don't know whether they tried enough to involve the patient on the healthcare team.

And so does that mean instead of saying, write the patient to come in should the patient be on the team and want to come in to get whatever it is, the test, or should they be recording their blood pressures at home? Should they even come in at all to get a piece of paper to go get?

So, you mentioned something that we're actually doing which is we are already, by default, the LDLs and the A1c's of the world the computer already knows they are due and can even use our algorithm, right, to say you're due and if we let them know electronically and have the orders already done electronically they don't actually have to come in and waste the extra time to come in and make an appointment, etcetera and they can be more command of their own health.

So, I mean, I'm just offering a corollary in terms of in addition to what we need to do on the professional side, maybe we can use all of the good things we've put in the category 2 the engage, empower patients and families to bring them on the team and certainly add to the workforce. But at any rate wonderful inspirational and challenge to all of us, but I think we also want to extend it to the "patients" as really the people. So, thank you.

Before we move on into the agenda I wanted to ask approval of the minutes if you have had a chance to look those over and have any suggestions. I put in a few edits. A motion to approve the minutes?

**W**

So moved.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Second.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

And any further discussion? Any abstentions? Okay. All approved?

**M/W**

Aye.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Any abstentions or disapproval? Okay. Now, let's go over the agenda and we're going to start out with

Robert Anthony giving us an update of the progress that is being made in EHR reimbursement, the EHR incentive Program, sorry. And then Larry Wolf is bringing back the taskforce report on Health IT workforce. As we all know it's not just the technology and it's not just the people who even put in the technology it's the people who have to use the technology to good effect as Farzad was just telling us about. We will have recommendations that we want to approve from that group. Joy Pritts is going to update us on the activities in the Chief Office – Chief Privacy Office and includes responding to some of the questions that came up before. So, let us know what's going on and what are the plans for the activities in that office.

Then Deven and Paul's show will continue with scenario number three and their recommendations regarding query and response in health information exchange. We'll conclude the morning with public comments, have a break for lunch and then John Halamka is going to talk to us, give us feedback from the HIT Standards Committee perspective. So, we made some requests from the Policy Committee over to the Standards Committee and they are working on those requests. They do have some points they need to clarify and John will be introducing that on his update.

And then Jodi Daniel and Doug Fridsma are going to update, continue to update us on activities in the Office of the National Coordinator. We are going to conclude the afternoon session with asking members for topics for future meetings so that we can prepare perhaps a briefing if that is what's needed or further discussion on topics that are important to members.

And then we'll conclude the whole meeting with time for public comment again as we always do. Any additions or corrections to the agenda? All right let's begin with Robert Anthony who is on the phone today. Rob, thanks for your update on the CMS EHR incentive program.

#### **Robert Anthony – Centers for Medicare & Medicaid Services**

Thanks Paul, sorry that I could not be there in person today. I know you have a busy agenda so I'm just going to go over some of the highlights of what we have this month. If we want to go to the next slide.

We'll start out just going through registration and payment data. We are now at approximately 390,000 active registrations as of the end of March, just as a reminder there are a total of about 527,000 eligible professionals who can participate in the program and about 5011 hospitals. So, you can see we have a large majority of hospitals at this point and a pretty significant number of eligible professionals. Next slide.

March was a very big month. We are continuing to process a lot of the folks who came in January and February for their second year attestation, so we have a lot of returning folks who have done a year of meaningful use. We have a lot of people who even came in their first time in 2012 but they came in at the very tail end of it so you're going to see some pretty large Medicaid and Medicare participation numbers for this month. You'll also see some for next month, but what I wanted to draw attention to here is that we have about 11,600 Medicaid eligible, I'm sorry Medicaid eligible providers, a little over 10,000 eligible professionals and 1300 eligible hospitals that have actually achieved meaningful use and you can see that we have that column there it's the second from the right that looks at meaningful use program to date.

So, I think when last we took a look at this we had about 8300 in meaningful use for eligible professionals. So, we see some folks who came in at the end of the year attesting to meaningful use and we're continuing to see that number grow. Next slide.

Overall, at the end of March we're at a little over 13.5 billion dollars paid out through to the program. Next slide. And most importantly, we have almost 260,000 unique providers participating to date. About 3800 of those are eligible hospitals that are participating mostly in both Medicare and Medicaid but you can see a small number of Medicare and Medicaid hospitals there.

But we have surpassed over 255,000 eligible professionals who are participating in the program, this is a unique figure, so people who are repeating in 2012 from their 2011 year are not counted twice in this number. We have gotten to the point where we are almost at exactly half of all the eligible professionals who can participate in the program are receiving a payment either for meaningful use or for adopt, implement, upgrade through their Medicaid programs. Next slide.

So, at this point in time we've got a little over 86 percent of all eligible hospitals registered for the program. Next slide. And almost 77 percent of those hospitals have been paid. The vast majority of hospitals have been – are dual eligible hospitals, of course we do have a significant number that have been reached meaningful use. There are about 1000 hospitals that are duly eligible hospitals that are at this point in time just participating under adopt, implement, upgrade. We expect to see that number in 2013 go up dramatically. Next slide.

So, we have a significant number of eligible professionals registered at this point about three out of every four eligible professionals are registered either under Medicare or Medicaid and you can see the breakout of what the exact numbers are over on the right. Next slide. As I said, almost to that point of half of all eligible professionals actually paid under either Medicare or Medicaid and this just shows the breakout of where it is. Next slide.

So just a recap, we're at three out of four eligible hospitals who have made that financial commitment to an EHR. About two out of every five Medicare EPs, a little over 40 percent, are actually meaningful users of EHRs and nearly one out of every two EPs have actually made that financial commitment to an EHR. This is actually a little bit higher it's over 255,000 Medicare and Medicaid EPs that have actually received an EHR incentive payment at this point.

We were not able, in time for the slideshow, to bring together what the April estimates were, but verbally I got them this morning handed to me. It looks like April is also going to be a very large month for us. About 50,000 eligible professionals will have received a payment in April now obviously all of those are not unique eligible professionals so you can't just add the 50,000 number to the 255, some of them are going to be repeats, but still a significant number of returning.

We will have about 150 hospitals that will have attested and received a payment in April and of course all of those hospitals would be new participants since they are doing their 90 days in the middle of the fiscal year. Next slide.

What follows here is attestation data. I won't go through all of this because, as you know, once we've reached something of a critical mass we're not seeing a huge amount of changes here from month to month, but if we go to the next slide I just want to highlight that what this data represents at this point is over 192,000 EPs who have attested out of the total number only 213 were unsuccessful with that attestation. We have 2,800 hospitals represented here so we have over half of hospitals for meaningful use represented here all of those have been successful. If we go to the next slide.

We're still continuing to see the same trends as far as what the most popular and least popular menu objectives are. We see drug formulas and immunization registries and generating patient lists for EPs, advance directives, incorporating clinical lab test results and drug formularies for hospitals. There continues to be a general avoidance of the transition of care summary for EPs and hospitals even as we are transitioning into the beginning of Stage 2 soon and then patient reminders for EPs and reportable lab results for hospitals. Next slide

There is some 90-day performance data here. We're continuing to update this month to month. As you can see in general we are seeing for folks who are – regardless of when they took part in their 90 days, they continue to score very high across the board and this is one of the things, as we've talked about before, that we were concerned about as we looked at this to see how many, to see whether early adopters scored much higher on thresholds than later adopters, but we continue to see, even in 2013, with eligible professionals who are coming in consistently high scores for thresholds for different objectives. That is true for eligible hospitals as well. We can go to the next slide.

It is true for both menu and core. There is a slight dip in some of these objectives as you look at 2011 versus 2013, but still well above the thresholds that are established for meaningful use. Next slide. As I say the trend holds true for hospitals. The primary difference here is that there is not as large of a gap between 2011 and 2013 performance, but we are still continuing to see, as I said, regardless of when they come in for those 90 days, consistently high performance across the board well above what the thresholds require. Next slide.

And this is the menu objectives. Again, we talked a little bit about the three at the bottom which are the public health objectives. As we're seeing more people come on board we are starting to see a little bit more of a leveling off, but certainly as some registries go on board or are not as available in certain areas we're going to see some fluctuation in those figures as well. Next slide.

We do have some returning provider's performance data for people who are interested in taking a look at EPs and hospitals who came in in their first-year and came in their second year. We're continuing to look at this data as we're processing more of these attestations in March, April and into May now. We particularly want to see for eligible professionals in their first year who did their 90 days as they move into a second year and a full-year of performance whether they maintain that high level of achievement with various objective thresholds and, as you can see, we are seeing an upward trend as we look at these objectives.

Overall, the 90-day period they scored very high. We're seeing a bump especially in certain areas like CPOE, ePrescribing and clinical summaries we're seeing an upward trend in some of those percentages. Again, everything is still consistently high in 2011 and 2012 but we're seeing a slight upward trend. Next slide.

The same is generally true for menu objective performance. You can see certain areas where it's definitely improving like patient specific education resources and submission to immunization registries and even patient reminders. Next slide.

Hospitals don't see a dramatic difference between 11 and 12 and in some areas you're actually seeing a slight dip as you move into the second year, a full fiscal year of performance with these meaningful use objectives. So, areas like recording smoking status or recording vital signs are seeing a slight dip. CPOE is seeing a very slight dip but still consistently very high across the board and we are seeing high-performance overall, relative to the required threshold. Next slide. And the same is true for menu objectives across the board. Generally you're seeing things hold about the same but a slight different performance overall for menu objectives for hospitals. Next slide.

I won't go through the rest of this. This is the aggregate performance data. This just goes through and looks at the averages across for EPs and eligible hospitals. We haven't seen any significant difference as we're getting more of this overall just in general the fairly high-performances. So, I'm happy to take any questions that people might have at this time.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Any questions? David Bates?

**David W. Bates, MD, MSc – Brigham & Women's Hospital & Partners – Senior Vice President for Quality and Safety**

I just wanted to ask do you have a sense of what the profile is of the hospitals that have not signed up? It seems like they must be fairly different from the remainder.

**Robert Anthony – Centers for Medicare & Medicaid Services**

Yeah, we've been looking at the data that we have through the attestation information and we've been looking at the data we have with RECs and then we've been having some conversations with various stakeholders on the hospital side and I think it's fairly safe to say that the hospitals that we're seeing that are challenged most at this time are hospitals that are in rural areas or that face particular resource issues such as critical access hospitals.

I think that we will – as we move forward and we start to engaging a little bit more down education on these fronts we'll probably get a better sense of some of the challenges specifically that are facing them. We're trying to look at particular objectives at this point that present a challenge for those types of hospitals. I think we'll have a fuller sense of what the hurdles are for those hospitals as we move forward.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Gayle?

**Gayle B. Harrell, MA – Florida State Representative**

Thank you, Paul and certainly the critical access and the rural hospitals are of great concern we see that in Florida in particular that we're having a hard time and I think part of it tends to be resource-based, you know, they don't have the upfront resources in some, in many instances.

**Robert Anthony – Centers for Medicare & Medicaid Services**

Absolutely.

**Gayle B. Harrell, MA – Florida State Representative**

Do you have any indication or is there any plan moving forward to assist in any way to have that up front resource to do the purchase or at least to start into something so that they can move down this road? You know that's what I am hearing at least in Florida.

**Robert Anthony – Centers for Medicare & Medicaid Services**

Well, currently the program isn't structured in that way. Its structured critical access hospitals get reimbursed on the basis of reasonable cost for depreciable assets. We did recently have a meeting, CMS and ONC with American Hospital Association and some of their representatives from rural and critical access hospitals about those specific challenges that were facing them. That issue did come up, the question of funding.

I think that one of the things that ONC is trying to do that we are trying to do is put together some education and some assistance that will direct them to some of the resources that are out there that will enable them to be able to secure funding to be able to do these types of projects, very often for them it is a question of finding a place to secure that funding. Sometimes for them it's an issue of finding grant monies for certain areas. There are some untouched resources that are available for this population. It's just a matter I think of us getting out there and making sure that people know where those resources lie.

**Gayle B. Harrell, MA – Florida State Representative**

That's key.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Any other questions? Good, thanks very much, Rob.

**Robert Anthony – Centers for Medicare & Medicaid Services**

Thank you all.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, next up we have Certification Adoption Workgroup recommendations on HIT workforce and Larry Wolf is presenting. Was Scott joining you?

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

No, unfortunately, Scott won't be joining me which is probably a very good way to begin this comment, this group probably only existed in some ways because of Scott's leadership but he is no longer involved with the committee and had to take on some other responsibilities. So, unfortunately, he's not here to talk about the work we've been doing over the last several months but hopefully we'll have a really good conversation here and I'll do a good job presenting the material.

And maybe I feel like the timing of this couldn't have been any better, Farzad's opening comments and your comments as well Paul, that we're looking at a people issue here. We've put the technology infrastructure in place and now we need to move it forward.

I'm reminded of the analogy of inventors, tweekers and implementers and some interesting analysis of the industrial revolution that the reason Britain was so successful was that they had a really deep apprenticeship program that created a whole generation of tweekers who could take the inventions, you know, take the steam engine and actually create it – modify it to produce the power needed to run a factory and so I think we're in a similar place here with Health IT.

We've put in place the infrastructure and now we have to get the people on the ground who are providing the care knowledgeable in making the small adjustments that make it successful. You know, the example Farzad used I think is really common and is the level of detail that needs – organizations need to get in to actually make this be effective.

Okay, we had a really interesting mix of participants in this Workgroup. We formed a subgroup specifically looking at training issues and so we brought in some of the ONC grantees who have been working on developing curriculum as well as people who are actually out there in the field through the unions and through organizations like professional organizations like AHIMA who are actually working with folks who are looking to advance their place in the workforce and some great contributions including one that surprised me from the Department of Energy who I normally wouldn't think of being on the leading edge of training programs.

So we had a broad charge to make recommendations to the Policy Committee and we'll bring some of those to you today. And specifically to do so within a year, so, we are within our one year timeline. Although, we're also looking for guidance from the committee in terms of where we ought to go next as a Workgroup or whether you feel like we've met the charge and can hand this off?

So we met many times and I would say there definitely was a period of storming and forming going on here as we tried to figure out what actually could we do as a Workgroup. Many of the topics we wanted to address became very clear were not Workgroup level topics. These were full-time job kind of topics and so you'll see that in our recommendations that we actually ask ONC to take some things on, other federal agencies to take some things on in terms of actually looking to carry these recommendations forward.

We did identify three sets of workers. There are those who are providing care. There are those who are the key people inside of the healthcare organization who are leading the efforts to implement the systems and to then use them once they've been put in place, the informaticians if you will. And then there are the IT folks who generally work more so in the background on infrastructure to make sure that the systems are up and running, that the wiring is in place, that the antivirus software is working and things like that. So, all three groups actually need to move forward for any of this to come to fruition.

We primarily focused on the current workforce, they represent the largest bulk of the individuals who need the training and they're in some ways outside of the initial efforts. So there are programs put together to prepare people for new emerging jobs, but not necessarily to address the on-the-job needs of individuals.

A lot of discussion at the committee about its soft skills that really make a difference. So, how do you make the transition to engage somebody in using the technology? A lot of us, because of the consumerization of IT, people come with sort of a different kind of understanding than they had 10 years ago say, you know, when you used to have to teach people to play a game so they would get mouse skills, most people have those interactive skills today from the rest of their life. So, in some ways we've moved forward in general on the tech side.

And obviously, there are training programs focused on how do you actually do the specific thing we're implementing the system to do. But we're changing paradigms here in many ways. We're introducing electronics as part of the job, not just an add-on to the job. So how do we bring them forward? How do we do that in then environment that supports real learning and not just get through the class and check off the boxes?

We noticed sort of the need for the follow-up. You got through the basics, you can do the things that you were taught to do and now you can document, you can, you know, do your job, but are you actually learning to use the technology. A lot of people get through that initial training they can do their job, but don't have the follow-up that might just be 30 seconds of learning from a peer "oh, I see how you do that."

I think if we look at how each of us have learned a lot of the skills in learning things like PowerPoint and Excel it's not because we went to a multi-day class, right? It's we saw somebody do something and we said "wait a minute, backup, what did you just do? I need to know how to do that too." And so, how do you engage that in the healthcare system?

So much of healthcare is individual-based. There isn't somebody partnering, there aren't doctors partnering with each other as they're documenting. So, there's not the opportunity to see someone use the system in a way that you go "oh, I just learned how to do a better job" or "I just saw how you engaged the patient and the computer wasn't a barrier it was a facilitator." So, how do we create those on-the-job situations that really encourage people to make really good use of the technology? I can talk about this for hours. So, I think I've hit most of the high points here.

We recognize there is a huge number of stakeholders here, many, many communities of interest. So, you know, this is not something that you necessarily need a post-doctorate in. This is things that you can learn in elementary school about taking care of your own health, about literacy, health literacy, information literacy to make good assessments, good judgments about the information that's available to you, huge resources in the Internet, lots of people getting information to support their own health care how do they make good decisions?

And this is also the training our future workforce. So seeing these things is really inseparable and job training is really something that we've been doing for a very long time. So this is not necessarily a new area and there are a lot of existing infrastructure both in federal/state government but also in the private sector and professional organizations that really can be brought into play and many of them are in fact incorporating new certification programs and new training programs and doing new outreach in their professional work to help people get up to speed.

I'm going to jump ahead into the appendix. There are a couple of things we thought were really cool and I don't want to miss them. So, one of the things we started down the road of was actually discussing competencies and I wanted to include this diagram and the reference as just a way to say that this is a pretty robust area and so for us to get into making specific recommendations on important competencies I think is really tough. I think the general direction of things like team-based care is in fact how we're looking to provide care is an important piece of the soft skills to communicate.

The examples of, how do you actually start to use the technology to improve the care, to engage patients, to move the dial on the outcomes we want to achieve, you know, again, going back to the example that Farzad gave us at the beginning. So, this is not necessarily the fine points of statistical analysis this is the very practical method of "I have patients who aren't coming back. What do I need to do to better engage them? When they do come back do they actually get the thing that I asked them to come back for?" So some, if you will, some one-on-one kinds of things that would make a huge difference.

The other is I think a very innovative career map that AHIMA put together and might actually be something that could be done more broadly. They surveyed their membership which is much broader than just people who do medical records and they said what has been your career path? What are jobs that you've had? And then flipped that around to say, so if somebody is in a job today what are the next jobs that they might consider?

And so they have a website with this interactive career map and you can poke around and it will give you a short description of the job and if you click on it, it will also give you the lines indicating what next jobs might be follow on jobs for you. So, it's a very interesting way to take some survey data of their membership and turn it into a very useful tool. There are also some general resources here, but I do not need to show you URLs. So, backing up to recommendations.

ONC has funded several workforce development programs and we need to learn from those programs. So, that is our first recommendation that the programs are summarized and results should be publicized. And then within those to look at what core competencies have been identified and let's bring those forward. So, there has been both work at the curriculum development level and also there has been experience of actually training people so let's see what we've got. What did we learn from those programs?

The third is that there are a host of resources out there and there are even some very good websites to make those resources available, but continuing to publicize those. ONC has made a big effort to upgrade its website over the years but it's not just ONC this is things the RECs can take on, this is things really that broadly could be taken on across healthcare because it's not just about IT this is really about how we're engaging IT as part of many of the healthcare initiatives the government has. Let's make sure we're skating to where the puck is going and make sure that we're actually looking to use these systems to address emerging needs.

So, again, as we're looking forward – to move forward with various healthcare reform initiatives, these are opportunities to further align with IT work at the level of how do people actually have the skills to do the job we're asking them to do.

We also recommended funding for new workforce programs. So, the government has a long history of funding healthcare education and to specifically look to include health IT as an area that got attention. Look at what's happening with the current workforce. So there are a lot of traditional studies of workforce things like turnover, things like what's happening in vocational schools and so let's learn from those and let's leverage those in health IT.

And finally, sort of one of those important I's to dot, the standard occupational classification system, which gets about an every decade refresh does not at all address health IT, it doesn't talk at all about the kinds of specific workforce that are those tweakers, that are the implementers. We have job classifications for clinicians and we have job classifications for technologists and we can certainly do the intersection of the technologist who work in healthcare, but we can't really look at the new jobs that are being created. We can't look at the CMIOs, we can't look at the informaticists, we can't look at the knowledge workers, if you will, who have specialized training and skills in Health IT because there are no job classifications for them.

So we look to ONC, we're suggesting that ONC actually take on that process as working with Department of Labor and there is a timeline in the appendix for that. This is not a time crunch activity we actually have many months to get engaged but not years to get engaged. So, this should be on the front burner maybe I'll bring that slide up. Yeah, so there is the revision timeline. So, this is very much a 2013 activity. Okay, so with that let's open this up for discussion.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Good, thanks, Larry. Questions?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

I may have a couple. One is the recommendations here talk about disseminating things that are already being done, do they cover the three workforces that you enumerated at the beginning the primary care, the care professional at the front end, the informatics professionals implementing these and then the technology, IS professionals. Do you think they are adequately covered already?

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

So, from what we saw I think the initial answer is "yes but." So ONC funded a variety of programs to do workforce training and they're mostly focused on that intermediate group if you will the people who have the combination of healthcare skills and IT skills and clearly that's a really key piece for going forward.

The others we then create a framework, but we didn't feel like there was anything specifically that talked about, you know, what do physicians need to know to be more effective in using these tools? What do nurses need to know? What do all of ancillary support staff, the health professionals of various kinds, need to know as part of their curriculum? So, clearly I think there are gaps in there.

But we felt a huge amount of work had been done but it almost felt like every call we were learning about something new and if we were doing this as our part-time job and it was hard to easily find all these resources maybe in fact efforts should be put into making them more available.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, one question whether there is enough to address what Farzad led off with in terms of helping the end-users leverage this valuable tool that we've worked so hard, as you said, to put in place.

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

Yeah, so, you know, most of what we saw were things that were generally speaking classroom, virtual classroom included, but there were sort of traditional education things and I think to accomplish the actual change that we're looking for we need sort of micro-training just-in-time things, you know, 2 or 3 minute YouTube video equivalents, if you will, that give people "oh, here's something I could do and it didn't take me all day, I didn't have to go off-site to a conference and it wasn't a big investment but actually fed what I was doing."

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

And the second question I had was, included in the workforce there was an IOM study on the workforce needs to address an aging America. And I think one of the things that we came up with is, gosh that's always thinking about other people doing things to the aging Americans. What about the aging Americans being part of that workforce, which again has that leverage, that magnification. Did the group think at all about the patients and their families as part of the workforce that needs to be trained and educated on how you could you use this tool?

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

So, we did have some conversations about that although they are not really reflected in these recommendations and I think to some of the earlier comments from the committee today the need to actually engage patients and see them as part of the team did come up as a recurring theme and, you know, how to do that, we didn't look at the kinds of public outreach things that might happen but our sense of where the schools might actually play into this does begin to address that as how do we as citizens start to take and make use of these tools.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, thank you, Gayle?

**Gayle B. Harrell, MA – Florida State Representative**

Thank you, yes, I thought that was absolutely wonderful and I think your dividing things up into really three segments of the workforce is key. Certainly, the primary one that is the direct hands one that has the most interaction with patients I think is probably the one that's received the least emphasis and when you have such resistance out there among some of our older physicians and providers who are very reluctant and feel that the computer and that EHR is a hindrance and not a help, I think that – and you have a lot of nurses on the floor of hospitals and things of that sort that really are still jotting things down on napkins and then going and putting it in the computer or having somebody else put it in the computer. We have to address that kind of...and that takes those soft skills that you're talking about to make that happen and I don't know how you do that, that doesn't –

You can't just put something up on a website to make it happen. So, I think that is a key component and that's where the rubber meets the road and making sure that you have some kind of training program out there, whether it's part of CMEs, that you can offer, you get the AMA to offer CMEs on this on hands-on kinds of things. How do you talk to patient while you're putting stuff in the computer? That would make a huge difference for reluctant providers out there and probably make the biggest difference in really helping to spread the word and get more people engaged and also get consumers engaged. And I'd love your comments on that Larry.

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

So, I agree that the whole need to actually engage people in the hands-on piece, CMEs do become a pathway to do that it's an existing infrastructure if you will and giving people – you know, in some ways it's a lot easier to go to the CME and learn about something than to try it in your own practice because, you know, there is not there is not any risk really in the classroom situation as opposed to actually engaging in care. But, I think it's really tough.

I'm reminded of some consulting programs that are based on taking clinicians who have expertise in a particular software set and making them available as hands-on partners, if you will, to other clinicians in other settings.

So to do the hands-on technology transfer of let me spend, you know, a morning with you shadowing you as you do your stuff contributing to what's being done. So, those are less, if you will, formal education programs but they're actually I think very affect in getting people the skills they need to do a better job and being done peer to peer.

It addresses a lot of the issues of, you know, listening and also speaking in ways that are helpful rather than, you know, the tech crew comes in and, you know, in 30 seconds shows someone something that they go "I don't know what you just did so get out of here I'm not interested, you're not helping me" as opposed to the peer who can actually seamlessly engage in the conversation and along the way bring in the tech skills.

**Gayle B. Harrell, MA – Florida State Representative**

Very true.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thanks. Judy? Oh, did you want to comment on this?

**Madhulika Agarwal, MD, MPH – Department of Veterans Affairs**

Yeah, I actually did. So, in fact, you know, exactly right on. We've had a lot experience with all of this. So, over 15 years ago when we were first implementing the electronic health record in the VA we had something that was sort of a boot camp and it was known as Camp CPRS. The whole idea was that, you know, by rogue force we were bringing the developers and clinicians together so that they could each learn from each other as to what's needed when we deliver clinical care and that has evolved into what later became known as the VA eHealth University.

And to this day I think that has had a very big role in a very successful implementation of the electronic health record because it actually also helped with the workflow which is what you are describing, you know, taking this information and then going somewhere else and learning. You know, in healthcare we learn a lot – I use the term osmosis from each other all the time. Someone is doing something and you go over and you sort of learn from them. There are various courses have been designed for that purpose called Tips and Timesavers which are enormously popular with the clinicians who are very busy and are interested in sort of cutting their time in half in the documentation and what's critical to them.

So, to that end, you know, structured environments created where a piece comes together to do the work and it's just a one-off, we certainly need those sort of sessions but more importantly on how is it that the nurse and the doctor, and the pharmacist, and the dietitian, and the chaplain are all going to be working in the same space and with respect to each other using the electronic health record is sort of critical. So, you know, I applaud you for all the recommendations that you have sort of laid out here. They are absolutely essential for any successful sustainable implementation such as what we are attempting to do here.

The second point was about the patients, I think it's going to be very important to have them as equal partners in moving forward. You know, there are web portals where they are sort of becoming much more familiar with it and some of it if it's intuitive it's easier but certain areas may not be so easy where a little more structure is going to be essential.

And lastly, I'll say that three or four years ago we recognized in the VA that we certainly needed a cadre of people, health professionals who needed more in-depth training so we partnered with AMIA the 10 x 10 Program and last year I think 36 such individuals who were from all backgrounds of health professions were certified and going forward I think they have 40 enrolled which we hope that in a year's time, in their own time – there is a huge hunger and a need and a desire by many of them to sort of come into these sort courses and sort of take that. So, again, you know, very nice work here.

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

Thank you.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

You've clearly struck a chord. Judy Murphy?

**Judy Murphy, RN, FACMI, FHIMSS, FAAN – Office of the National Coordinator**

Sure, Larry thanks so much for your leadership in this area and I've got a couple of questions about existing things that we've been doing to see if the group addressed any of that. So, one of the programs that we had funded through HITECH was the curriculum development and so we ended up with this really good, really robust curriculum that is now really not funded significantly going forward. Was there any discussion about the value of that and whether or not that is something that we should be continuing in 14, 15 and beyond?

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

So, we didn't really assess the value or any issues with the curriculum. So, I really don't have much comment to say about that. One thing that was kind of a question was, you know, many of the programs, the community college programs for example, if I remember right, were reporting that their greatest success was with tech people who are learning healthcare rather than healthcare people learning technology and my experience in healthcare provider organizations actually have been the reverse that we get much better results when we take healthcare people and teach them some technical skills and bring them into our technology groups and so I wonder if in fact the setup of going to classes and getting certification is in fact creating a bias in what we're learning rather than actually supporting the need that we've got.

**Gayle B. Harrell, MA – Florida State Representative**

I'd like to add into that too and what I have seen from practical experience on the ground in the communities and what I hear across the State of Florida is that a lot of those programs gave you a certain level of technical knowledge but did not give you the OJT, you know, they were mostly virtual and when you come down to the real practical level of using things you need that hands-on training and that was one of the lacks that many students would express to me.

And if we move forward with additional ONC funds, additional courses and scholarships and things of that sort, which I think is an excellent idea, we need to make sure we have that practical OJT as part of it, because without that people have a knowledge base, but when it comes to practical application you don't have it.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thank you. David Bates?

**Judy Murphy, RN, FACMI, FHIMSS, FAAN – Deputy National Coordinator for Programs & Policy – Office of the National Coordinator for Health Information Technology**

Oh, I'm sorry, quick second question?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Oh, sorry, yes?

**Judy Murphy, RN, FACMI, FHIMSS, FAAN – Office of the National Coordinator**

The second one is related to certification so you kind of brought that up, you know, we had a competency exam and certification, but it's in a world where there's other certifications, right? So, as recently as this year there is a new, for example, medical specialty now around medical informatics, nursing has had a program for a while, AHIMA has had a program for a while, you know, those kinds of things. So, was there any discussion about the value of those multiple versus single looking at harmonizing them or just let 1000 flowers bloom?

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

So, this is my jaundice view of that is certificates are very important for helping people get the job interview but not necessarily get the job or do the job and so I think in that sense that multiplicity is fine as long as there actually is some kind of basis for the certification so that an employer could go "oh, okay so you did pay attention to this, you did learn a body of things, now let's see if you know anything" right? So, it's like the first hurdle.

**Judy Murphy, RN, FACMI, FHIMSS, FAAN – Deputy National Coordinator for Programs & Policy – Office of the National Coordinator for Health Information Technology**

But no specific recommendations?

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

No.

**Judy Murphy, RN, FACMI, FHIMSS, FAAN – Office of the National Coordinator**

Okay, thanks.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

David Bates?

**David W. Bates, MD, MSc – Brigham & Women's Hospital & Partners – Senior Vice President for Quality and Safety**

I wanted to ask if you had a sense of sort of what the relative gaps are between the three groups, in other words, are there – do some of the groups need particular attention and especially are there gaps that are not going to be addressed by market forces. I can imagine for example that market forces might pull in more people from the technical side, say. Did you talk about that?

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

So, I think we talked about what felt like two very distinct worlds, right, we talked about the world where people are going to get training and we talked about the world of on-the-job. I don't think we actually had any grand breakthrough of how do you bring the things that are happening, the training programs go away for training into the on-the-job things other than the notion of just-in-time micro classes so that you don't have to be gone for a long time you can learn something quickly.

And in general the fact that we've got a very big base of people in healthcare today who have grown up without these tools and even if they had tools in their training and have been using them, they've been using them, if you will, to do the old job not to do the new job. For a lot of people the IT, the information systems are a way to put information and it maybe gives them a work list or a to-do list or it pops up reminders, but that next level of how do I actually use it to improve outcomes when it's not just as simple as a pop up this reminder, but redesign the workflow or learn to ask a good question that those are much tougher things.

**David W. Bates, MD, MSc – Senior Vice President for Quality and Safety – Brigham & Women's Hospital & Partners**

So, let me just follow-up so your sense then is that the need is more for micro-training of lots of people than for new –

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

Yes, my sense is that the, you know, the graduate program in informatics should get funding, should get support but it's not the big need but the need is for the practical, the hands-on and that's the base of the folks that we need to really address and it's a huge number of users of systems and it's not just on the IT side it also ripples to all of the kind of management issues of how does management take on the potential that it now has with these systems that have been put in place and actually use them effectively to improve things. So yes, back to its less about the academic programs, which are really important, but more about how do we actually make this effective for people who are out there delivering care.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thank you. Judy Faulkner?

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Yeah, a couple of things, I really agree with you on the emphasis on making sure that the everyday user is trained over the graduate classes and I think a lot of organizations kind of look at those graduate classes as maybe their hope that if they go that direction then everything will work because those will be the folks who do all of this. Maybe to some extent we need to go to those graduates, since that is the way many groups work, maybe we need to go to the graduate classes and make sure they understand this better so they then can be the folks who make sure that this gets done.

I liked your pyramid and I thought it was interesting when you said it is stronger to get a healthcare person and train them than an IT person because when I look at your pyramid the bottom two things, personal effectiveness and academic competencies are things that are going to be hard to teach people in a short period of time. Those are things that people have learned throughout many years.

And so, I'm wondering two things, whether really the answer is as long as you meet that bottom criteria then if they have health care competency you can teach them what they need to know for IT. But, my thinking is that we can go a wrong direction if we don't find how do we validate that the right people – that the people are the right people because they have those bottom competencies, because I think if you don't build on them you're not going to get at the top. So, I don't know how you're doing that one.

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

So, this is an example of the depth we did not dive into. I think it's really important. I mean this pyramid was put together by people who work on this a lot and I think in fact it's a useful notion of you need some basic skills to then build on the more specific technical skills. And in this case there is a combination of healthcare skills and IT skills, informatic skills.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thanks, Art?

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

Yes, thank you, Larry I think this is an excellent presentation you generated a lot of great discussion here. I actually don't have a question for you, but I have a question for Dr. Agarwal who just told us about what is the excellent opportunity that you've taken advantage over the last 15 years at the VA and going back to Paul's earlier comment about consumers and engaging all of the consumers. Has the VA done anything where they've tried to look at consumer tips and timesavers? How have you tried to engage the veterans in using a system that you have done so well within your own organization? |

And then I have a question for ONC staff is to say do we even know what are the consumer competencies that we would like to see if we were to move forward and try to engage consumers better. Is that even established yet and what might we do to improve that? So, maybe we'll start with Dr. Agarwal?

**Madhulika Agarwal, MD, MPH – Department of Veterans Affairs**

Sure, thank you, you know, that's an excellent question. Since we have a couple of modalities that are very much veteran facing primarily starting off with the web portal which is called My HealthVet we've had constant stakeholder input into improving it and in fact I'm blanking on the name of the survey that's done routinely to assess the feasibility of what the content is and how we are deploying it and using their feedback in improving the quality of it and I can get that name for you shortly.

But, the second part, which is something that we are just about ready to launch and I may have previously mentioned it here, is a whole new initiative of giving out the caregivers of those seriously injured veterans iPads which are caregiver applications and this I think is going to give us an enormous opportunity to sort of see firsthand as to how they interact and what the usability and the feasibility is going to be and what areas are going to be needed to be defined further.

So, there is going to be input based on that as well as a whole host of other mobile applications that are currently underway which do have a component that consumer feedback is going to be critical because it's an iterative process, we don't know all the mechanisms on what's going to make, you know, something work and why. So, this is a lot of ongoing sort of continuous learning that we've undertaken.

**Judy Murphy, RN, FACMI, FHIMSS, FAAN – Office of the National Coordinator**

In terms of the ONC campaign, if you will, to think about competencies and changing the way people think about their own health and their own healthcare. We've had this framework called the three A's and it relates to access, action and attitude.

So, we don't have them specifically written out in competencies but the idea would be in the access space that you'd get access to your data and that then would allow you to take action. And so the action could be things like shared decision-making, it could be helping, again make decisions about your care and/or your health taking control of your health yourself through, you know, exercise programs, eating differently, those kinds of things, as well as the healthcare component making sure that you're getting the right kind of care.

In the attitude space, you know, this has to do with really engaging those people who otherwise wouldn't think that it's important for them to be engaged in their health. So, there is a whole proponent of folks that don't even realize that they could be making a difference in their care by getting access and taking action.

So, the attitude component – we did a video that some of you might have seen, a 1 and 3 minute version that's been out there that a lot of healthcare organizations have up took and have on their closed circuit TV systems and those kinds of things, but again, not really written out in competencies and that's really not a bad suggestion actually to think about it that way.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Well, just like you could talk about it all day it sounds like this committee could talk about this topic all day and we really had broad discussion. Let me start with Farzad and with something you said as well. So, I think is his anecdote from this morning about the IOM meeting and his 50-to-5 percent says how much this is crucial to creating synergy from this incredible amount of work that was put into putting the tools in place and now we have to use them and I think what we're saying – that's where the discussion focused on is it's the people who have the tools that need the help.

I love the idea about micro-training because I think that the only thing and that was a very interesting observation you had which is the programs we put into place only serves one segment, it's the technical folks trying to learn a bit about healthcare when we had this massive workforce of healthcare professionals needing to use the technology better.

You invited us to say, hey, should we stop here or proceed. I would get the sense from the committee that there could, and this is where Farzad be bolder recommendations in terms of how do we leverage this incredible – I mean we went from less than 5 percent to half in three years that's incredible, but we have the 95 percent to do and I don't know a way besides deliberately training on the job, as Gayle said, I don't know that it's just leaving the technology in place and it'll just happen automatically. I know certainly our experience and a lot of – experience as well you just have to add – it's not that we trained to know how to use this but we can learn thank goodness and there a lot to be gained from that training.

So, I would sense and I would say and suggest and see what the group thinks that more could be done in terms of concrete proposals that you even said here and that have been suggested to embolden the recommendations and probably lead to a different way of thinking about what is workforce training and particularly for whom and it certainly would include the patients and families as part of for whom, but does the group agree with that?

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Just one comment on that. There are certain competencies that really are not specific to the electronic health record that are being used and many of the examples I gave are in that category and we really should, I agree with you, be bolder about what are some of the – just as technology brings new challenges it brings new opportunity and possibilities.

So, if we're talking flipping the classroom and massive online open courses and games, you know, we did a game for security that was very well-received, you know, a modeling game where you're – you know, it's like SimCity for healthcare, right, where you have X number of resources and you want to get your patients with diabetes controlled and, you know, what do you do and what happens in modeling that forward those – I think we can think about ways of teaching population health management principles and so forth in a way that can meet the challenge or the scale of the challenge.

And some of this I think, you know, what we did with electronic health records was we said, you know, it actually needs people to help people and the regional extension centers showed that hard work can scale across a country and help 140,000 primary care providers in those small practices and the critical access hospitals and the rural health clinics make that transition. My hope and dream is that we will see a business case for those types of services and potentially the extension centers themselves being able to offer or other groups QIOs or consulting groups or whoever serving those needs if there is a business case to do so.

One particular challenge that we have in terms of any trainings that are not offered by the vendors themselves and many of the vendors really are in terms of the EHR itself they're the ones who provide the training has been the specifics of that system. So, getting trained on CPRS doesn't necessarily help you implement, you know, some other commercial off-the-shelf technology and in fact can sometimes, you know, teach you to expect, you know, things that you're not going to see. So, it can be confusing.

So, I wonder if there are maybe two categories. There is one kind of some of the more general skills and themes around – particularly around workflow adjustments and population health management and so forth that I think we need to be more creative on. But on the product specific training side if folks and I see Judy has her flag up have some ideas about how to improve that. To you Judy in terms of how we can provide whether there are creative ways that the vendor specific training could be offered, supplemented that the workforce that could then work on an Epic in your case implementation be made available.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

One of the things that I think is most important that has to be done and I don't see it being done as much as it should be, is that you need the same specialists to train the same specialists. So, instead of generic training, which is I think what many vendors do, if not most, where they teach generic classes, the dermatologist or the neurologist can learn better and learn in a much shorter time if we train one dermatologist or one neurologist well and that person then goes and gets the rest of the pyramid trained, so maybe that person trains a few others and they all go and train all the rest. I think it's the specialty specific or even role specific training that needs to be done. You're nodding your head, yes, Paul.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Just to backup what Judy says it's not generic at all, it's not even generic about a product it's really the workflow which is the core thing that Larry's group has been taking about and the reason why specialists training specialists has worked is because they know the workflow and the difference between having – well, I mean, other people coming in to try to train your go live it just doesn't work.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Yeah.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

And I'm sure – confirm this, the optimization phase that comes after is so, so important it's typically more one-on-one and in fact we're investing millions of dollars to do one-on-one period. Just because that's what changes behavior, Gayle mentioned this as well. It just isn't a classroom exercise it is learning how to both change my workflow and learning how to make the tool work for a workflow in neurology or whatever that makes the difference. You've got change the 95 percent. You really have to change the workflow from then on and it really doesn't work in the class.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

And part of it is not just the training. If you step back a step you need to make sure that when you walk into a room and you look at a screen you can say "oh, I must be in dermatology, look at that screen I must be in neurology, look at that screen." If the screens are specific and that within that each user has gone to the personalization lab or whatever you want to call it, so each user then says "how do I make it work for me?" Because what we really need to do is take it down to that level of the specialty and of the individual or else it won't work.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Neil?

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Just, you know, I don't think we've addressed how Farzad started this discussion though. You know, I think we're talking – a lot of the discussion is about putting things into the system. I mean, that's what a lot of us have been talking about and, you know, what I think is begging is so if the dermatologist is training the dermatologist what are they training them to do? To document faster, better, quicker or are they training them to get better outcomes with the things that they're doing and how to use the data and how to generate reports and how to figure that stuff out. Because I think we're doing a tremendous amount of people teaching each other but not necessarily teaching each other what they need to know in order to improve the care that they're giving.

They're teaching each other lots a shortcuts and quick tips and things like that to get their work done more quickly, but it's the work we used to do and it's not the new work and I think that's where the huge challenge comes in and it's why – you know, Farzad opened up and said every time we look at something, you know, we look terrible it's why years into this every time we look at something we still look terrible because, you know, we're doing stuff across a broad range of things and we focus so much energy on the workflow design that's about just getting the work done quicker and faster.

So, I think that – so that's one point I wanted to make and the second is I would love to see the data that we get presented every month cut by vendor, you know, the attestations and the things that people are doing successfully because I will bet that there is huge variation in the ability of the products to assist the people in accomplishing the work that we're trying to accomplish.

And I remember saying this at one of the first Policy Committee meetings, what is that now four years ago? To say what is the responsibility of the vendors for helping people to actually achieve what it is we're trying to achieve? I'd love to see what the LDL levels are of the people in these different groups cut by vendor because I think then we can begin to start to think about best practices in workflow and I don't think, you know, it would violate things tremendously.

I don't think any of us are trying, hopefully, not to sell our products based on the fact that, you know, we can get higher rates of LDL control. But that in fact people could share some of the information about workflows that are built into the systems that actually work to improve care.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**  
– risk adjustment based on demographics?

**Madhulika Agarwal, MD, MPH – Department of Veterans Affairs**

If I may, you know, I completely agree with Neil when he said the first part and I think it is a two-step process. You have to improve the workflow to get that buy-in it takes time. But the second part is actually key to improve the outcomes, what is it that you need and I think it's a journey but if you can't get the first one right you're not going to get to the second and having that experience I will say that it's absolutely – you've got to take the first steps and then you start to run.

You have to improve the workflow to get that buy-in from those many people who are going to do that work and then subsequently you've got to have those tools that Farzad was talking about on how you do risk stratification, risk assessment so that you can have targeted interventions which hopefully get you the right outcomes.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

David where you –

**David W. Bates, MD, MSc – Brigham & Women's Hospital & Partners – Senior Vice President for Quality and Safety**

So, I also think that the biggest need is with the broad group but I'm hopeful that market forces will help us kind of get to where we need to go especially with accountable care there will be incentives for people to actually do better with their LDLs. I feel like entities like ONC can play a catalytic role by sharing some of the success stories and helping people find each other.

I do feel like there is a big need for more support to train some specific groups and the level of training for informatics has essentially remained – the level of support for training in informatics has remained the same. We need more people working in informatics. If we don't have those people the systems are not going to get better so that's I think a specific need.

I think we also need to do a better job training the people who are going to lead efforts like the CMIOs and Chief Nursing Informatics Officers and they need more than what we've been talking about. I also think that Larry's recommendations about the standard occupational classification those are really, really important that's something tangible that we can do and, you know, I think that's a very important recommendation.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Gayle? Okay, Gayle.

**Gayle B. Harrell, MA – Florida State Representative**

Thank you, I just wanted to say I think this is a two-tier system first you have to get the workflow down, you know, as we said you have to have that down, but you also need that second level and whether it's Stage 1, Stage 2 or Stage 3 I think we're moving towards that.

First stage capture the data, you know, you've got to do that, but now I think as we're getting into Stage 2, you know, we have that interoperability built in, by the time we get to Stage 3 that ought to be an expectation, you know, and that's – and be goal oriented not process oriented and I think that's where this committee can have a huge impact and also in funding of training.

So you need to train that basic level so that you have that ability to do it and we are still unfortunately at the educational level and training level at Stage 1. We haven't even gotten to Stage 2 to make sure you've got the workforce out there who have that hands-on knowledge can do it, but you can't start thinking about ways to use things effectively until you really get the very basics down and we're not there yet. I go into hospitals all the time we're not there yet.

I go into, you know, large practices or, you know, integrated healthcare systems and the resistance out there, you know, is very difficult. And on the consumer level you need that little push/pull, you know, a push from consumers as well. So, it's an interaction you have to take place that's going to push the provider down that road, but we're still not even basically finished Stage 1 at the provider level.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

I think one of the regrets is that each of us are learning the same lessons over and over again even amongst the major health systems. So, it's nice that there is a dissemination but I don't know that putting more books out there is going to do it. I think it's much closer to your micro-training, Larry, I mean; we're just all learning the same thing painfully. So we all go through pain then we learn and we're not proactively doing it.

Going back to your SimCity recommendation, so for example, the story you told is well first they wrote patients and 50 out of 700 responded then they tried – wouldn't it be nice to have SimCity that said, well when you have a group together what are we going to do about this? Oh, why don't we write them? Let's look it up, well you get a 5 percent return rate. So, in the example I was sharing is our health maintenance automatically without human intervention says, hey, you're due by the way the order is there you don't have to go through all the rigmarole to go through us which the barrier and we had a 25 percent increase in the people getting in this case, mammograms.

So, there are ways but that's another way of sharing is if we had this SimCity where, oh, so one of the people tried this, how do you do that instead of go looking at the literature just go to the SimCity ONC and figure out here's what other people have tried, this is what they've gotten then you can at least skip to the top and bypass all of the other painful learnings. But, so, there are clearly innovative ways we can do this.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

I mean, in terms of the micro learning the other thing that my kids are at the age where, you know Khan Academy is a part of our lives and, you know, when there is a discrete lesson that they want they look up that lesson and they learn, you know, in a very clearly explained, you know, in terms of how to do that and I think it is a little closer to the micro-training than, you know, sitting in – you know, or supplementing that classroom experience.

But again, I think there is a challenge in terms of – I don't know if a champion or someone who really knows how to do this were to try to record a little video about how I do population management with my tool, you know, would the vendors be upset if – in terms of intellectual property or, you know, showing the product or not showing the product right or whatever? I mean, are those real world, you know, can people do that? Neil, you have a workflow now can you show people what you do?

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Well, we're not supposed to. I mean, people outside of our – people in our center we can, but, you know, we're not supposed to publicize, you know, we couldn't put a video that showed screens and put it out on the web.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Well no –

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

No.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Yeah, I think every vendor's screens are considered intellectual property, but you could do it to those who use the same tool and that's an interesting thing because for one user of Vendor X to see how you use Vendor Y doesn't make much sense anyway. So, really its best use is within its own community.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

You know, there's an analogy here in the way people learn to fly. I was speaking to somebody who is a pilot and there are certain basic fundamental principles of flying but you have to get checked out and certified in every single plane that you're going to fly if you're a commercial pilot and you go through all of the emergency, all of the procedures in every single plane because it's so different in the way things respond and I think we're sort of in that same piece where there is a piece of what we do that kind of flows across everything, but so much of what we do is so specific to the products that we're working with which is why I brought that up before.

Because, you know, when you talk to your colleagues and stuff like that and you talk about what you can do or what they can do you realize that the functionality and the workflow and the ease with which different functions can be accomplished is very different product to product.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

That's a really interesting point Judy in terms of a potential way forward that if there was a one-stop shop for the product for which you had the license, right, and right now there's tremendous variability between vendors in terms of what they make available for their users groups and other online trainings and so forth.

I wonder if there would be a way to have the EHR Association or HIMSS or other groups take on this challenge of is there a way that there can be, you know, a designated place where key concepts, you know, best practices around key concepts are – and across all vendors but you only need to see the one that is your product. So, dealing with some of both the legal but also kind of the pedagogic aspects of that education. Do you think that is something that is worth doing?

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

I don't think it would work very well and the reason is when you watch the everyday user, the everyday user isn't going to leave what they're doing every day, the workflow that is so important to get done first because then you don't have time for the rest of you don't get that down. I don't think they're going to leave it and go there and then come back. You need something that is built into what they're doing.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Just the variability in terms of how well different vendors integrate that into –

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

For example, I think most vendors have user webs, we do too, yet it tends to be your high-performing users who use the user web not the everyday user who is just struggling through who goes there and uses it and so you don't get the right audience then.

**Neil S. Calman, MD, ABFP, FFAFP – The Institute for Family Health – President & Cofounder**

There is also – outcomes people have been able to achieve using different models and workflows and so you could easily adopt something and say, wow, this is a great set of orders and whatever, but it's not – you don't know whether it achieves better results.

So, I think that being able to start with the outcome is going to be critically important in this stuff and we've got to be able to figure out a way to report the outcomes that people are able to accomplish in various places and look at actual best practices with those outcomes.

I mean, that's what we're doing internally within our organization, but that's only a small sampling of potential ways of dealing with problems but if you did it, like you're trying to do with LDLs or with other things, you know, in a larger group of people you could actually begin to look at best outcomes and try to figure out what workflows support those that's what I think we've got to do.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

It's the tweakers that Larry talked about.

**Neil S. Calman, MD, ABFP, FFAFP – The Institute for Family Health – President & Cofounder**

Huh?

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

It's a tweakers that Larry talked about.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

There is often a "not invented here syndrome" too that we see which is many times we've seen one group report on some really good outcomes, another group try to take it and share it but when they bring it back they're told, well that might be good for folks but that's not how we do it, that's pretty common.

**Gayle B. Harrell, MA – Florida State Representative**

Yes.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

This is been an incredibly rich discussion but I think it's a reflection of the importance. So it's the 95% gap, it's the pain, but it's also the need to systematically and boldly do something different from what we're doing. I mean, doing more of the same probably isn't going to make it better for any that follow.

So, I think this is a real opportunity looking at it that way to make some recommendations and potentially some programs that actually help the half that haven't even begun the journey and not that the half who have already made their first meaningful use objectives don't have more to learn.

So, I would suggest that there is incredible opportunity to come back with actually folding in some of the concrete suggestions that are made here and turning them into recommendations moving forward. How does the committee feel about that? Yes? Larry is that a –

**Larry Wolf – Kindred Healthcare – Senior Consulting Architect**

Yes, I actually probably want to engage a few folks to get some clarity on where value might be.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Sure. I think the transcript will help because I think there were a lot of really good suggestions that could turn into recommendations and they're very thought-provoking.

Well, thank you group for doing that. I did have some advance peering into some of the presentations and I think some of them will be shorter than scheduled so hopefully we won't be too far off time. Thanks, Larry, and thanks to the group. Next, Joy Pritts is going to update us on activities in the privacy office.

**Joy Pritts, JD – Office of the National Coordinator**

Good morning. There we go. Let me make sure I know what I'm doing here. Okay. So, it's been a while since you had a last update from my office. I think it was last fall was the last time and as usual I will start with some of the major policy initiatives that have been brought to fruition in the meantime and then I'll move onto what we call the small P, the programmatic and more internal policy work that we're doing. So, since we met last fall, unless you have been out of the country for several months, you would not know this, but the OCR did publish the final rule on the HITECH modifications to HIPAA in January 2013, yay. The compliance date for that is September 23, 2013. So there are still several months available in order for people to bring themselves up to compliance.

Some of the key provisions in what is fondly referred to as the omnibus rule because it did deal with a lot of different issues include a finalization of the breach notification rule which changed the notification standard to a more objective standard. It extends the use and disclosure of the provisions of the HIPAA privacy rule and most of the requirements of the security rule to business associates as well as the contractors and subcontractors of those business associates.

It clarifies the patient's right to access their health information in an electronic form and among other things it also gives patients in accordance with the very specific mandate in the statute, the HITECH statute, the right to restrict providers from disclosing health information to plans when paying out-of-pocket.

It is our understanding that OCR out of the Office for Civil Rights, which is in charge of enforcement of HIPAA, is in the process of developing guidance in this area of the HITECH modifications but in the meantime I would also really seriously recommend to people who have questions on this, if you have the time, to read the preamble to the final rule because a lot of information is in the preamble and it does explain where the HHS is headed on those issues.

Another major policy initiative that we've been getting a lot of questions on lately is the White House's – excuse me, I'm only getting half – I'm not getting the entire title here can we scroll down a little bit? No? Okay, so I will just tell you it's an executive order improving critical infrastructure for cyber security and it was published in February 2013 and – I know, but I wanted them to see it, but you'll have a hard copy. It's executive order 13636, it was published this February. This is for those who are familiar with the old presidential initiatives on this; this is the replacement for presidential directive 7 – yes, this is 13, there you go, 13, 13636. So this – there are – what this does is it itemizes these sectors – that's okay, it's easier this way. It itemizes many of the sectors which are considered to comply to the critical infrastructure in the United States. Health and public healthcare are included as critical infrastructure. This is not new this has been the case since 2013 and there is a link there to where you can read this executive order should you be interested.

Some of the key elements of this are that it increases the government's ability to share cyber security information with private sector critical infrastructure, as well as state and local governments. It charges the National Institute for Standards and Technology, NIST, to develop a framework to reduce cyber security risks.

It also identifies critical infrastructure that the government will be sharing this critical information with and what it does is it focuses on the greatest – the critical infrastructure which is at the greatest risk. They define this as being where a cybersecurity incident could reasonably result in catastrophic regional or national effects on public health or safety, economic security or national security. They had set a very high bar.

So we have been receiving a number of questions in from hospitals for example, wondering if they're going to get the call, the secret call from the Department of Homeland Security, and I would say that that is highly unlikely at this stage. It is a very high bar. As somebody in the meeting said, if you have to ask you probably aren't, but that should give people some reassurance as to where this is. HHS is involved in the Workgroups that have formed around this initiative so, you know, the health sector is well represented.

Another initiative that has been ongoing that people have expressed a lot of interest particularly from this committee is the National Strategy for Trusted Identities in Cyberspace and NIST issued a number of grants in this area last September and one of those is a health related pilot. And we received this information from NIST so this is probably second or third hand information. So, I'm not sure if you ask any questions on this I could answer any more than the information on the slide at this time.

But, we do have staff who are following the health related pilot as it is progressing. Resilient Network Systems is the organization that is leading the health related pilot for NSTIC. It has formed a partnership with a number of organizations you can see here, it's a wide range from the American College of Cardiology to the San Diego Beacon eHealth community, as well as entities that actually do a lot of authentication and patient ID proofing, such as LexisNexis and also with a trust organization, Kantara Initiative.

So their plan is to implement a trust network infrastructure that will enable convenient multifactor, on-demand identity proofing and authentication of patients, physicians and staff. The pilots use case will facilitate patient centered coordination of care among a select group of primary care physicians and cardiologist by enhancing existing automated systems. So, they're not starting from scratch, they're just enhancing a lot of things that are already in place and they're using it for electronic referrals and transfer of care will be some of the first things that they're working on as well as clinical decision support.

Here are some of the pilot participants and then here is a visual for those of you who are visually oriented of what is proposed. And this is where, if you ask me a question, I will probably not be able to answer what all these different components do, but as you can see down in the left hand, there is a third-party authentication and authorization services, which are a key component of the NSTIC approach, which is that it's basically, for you who know, it's the potential for a kind of single sign-on across organizations on a very wide scale not only for providers but hopefully also for individuals and patients at some point.

Right now the Direct – they are using Direct as their exchange mechanism and up on the top of this screen over kind of towards the left there is a Direct gateway you can see that has been prototyped and tested and there are other pieces that have been prototyped and the agreements are in place for the use of the directories, attribute providers and eReferral tools.

So, this project was funded for one year, there is an option year for a second year of funding. The first year of funding expires in September and we will keep you posted on the progress that is made on this and there is – you know, this is really hands-on in the real world testing that's going on, piloting that is supposed to be going on.

All right so those are the major what I like to call the big policy initiatives that have really come out since last fall. And now I'll turn to a snapshot of some of my office, the Office of the Chief Privacy Officer's research and internal initiatives. And I'm going to focus on three key ones today, although we have more, including the – well, we have more, including a message campaign which we hadn't brought but it so resonates with that I feel like I need to talk about it, because earlier today we were talking about – the panelist talking a lot about the different responsibilities of the stakeholders and that really rang a bell with me because we have started a – engaged in the last year on a privacy and security campaign and our key message to everybody is we are all responsible for privacy and security and everybody has a role to play. So it is a message that is very consistent with what this group has been saying.

So, the first project we'll turn to is the data segmentation for privacy and to do some context setting, as you will remember, this project really originates back in the HITECH Act itself, section where it – the HITECH Act amended Public Health Service Act, section 3002, and it specifies that this committee will make recommendations regarding technologies to protect the privacy of health information and promote security in a qualified electronic health record including for the segmentation and protection from disclosure of specific and sensitive individually identifiable health information with the goal of minimizing the reluctance of patients to seek care or disclose information about a condition because of privacy concerns in accordance with applicable law.

To further those goals the Tiger Team, this Policy Committee's Tiger Team held a hearing on technology back in September, in summer I think it was June of 2010 shortly, not too long after I arrived actually, it was an all-day hearing and there were a number of different organizations that participated and explained how they were using various technologies and it became very clear at the meeting that they were all doing some kind of interesting things but nobody was doing it in a standardized manner.

Out of that hearing there were recommendations issued from the Policy Committee to ONC in September of 2010 which said that the technology is promising but in its early stages and that ONC needed to further – that there was a need for further experience and innovation for granular consent that ONC should make it a priority to further explore these areas and to find evidence “such as through pilots” for models that have been implemented successfully. We initiated this project and we gave our last update on this project in the fall of 2012.

So I'm going to focus primarily on what has happened since 2012 rather than go through the entire project history. It did have the data segmentation privacy initiative is an initiative of standards and interoperability framework at ONC. There was very strong community participation in this project. There were 306 participating individuals, but there were 100 committed members, which means that there were 100 people who actually very consistently attended the meetings and participated in the various workgroups that formed. And there were 94 participating organizations.

Among the initiatives accomplishments is they focused – this happens with all of the standards and interoperability work, they first established a – they do some pre-discovery, which we had done some of through our hearing, but they also do – they develop use cases. What use case are they going examine?

And in this case they developed – the community developed a privacy use case document, which included electronically implementing existing laws including, but not limited to, 42 CFR Part 2, which is a federal confidentiality of alcohol and drug abuse patient records and Title 38 of the US Code, Section 7332 of the US Code, which deals with some of the information that is protected by the Department of Veteran Affairs and it includes not only substance abuse information but also other types of data including the sickle cell anemia and HIV.

Two of the reasons why these laws were focused on as use cases were first, they're very broadly applicable. They have to be complied with – unlike there are many state laws that also require additional consent, those vary very much from state to state so these are very broadly applicable and they apply in every state and there are few state laws that have actually overridden these provisions. So there was thought that there could be a lot of leverage by focusing on these.

But they also recognized that when they were choosing these use cases that the same principle applies to any laws that exist that give individuals the ability to consent over specific pieces of information. I will also say that there is a proposal here, one of the use cases that was considered but that was not adopted, was to facilitate the marketing and potentially not sharing of the information that is the out-of-pocket paid information under the HITECH proposals, under the HITECH Act and the reason that was – part of the reason that was not chosen was that at the time the regulation when this first started, the regulation – although the Act was clear the regulation was not clear as to what direction was being taken. So, the group did not feel that there was a – they were comfortable enough to know where that was headed that they would work on that issue but it was considered.

In addition to the use cases they also developed an implementation guide. And they also did an analysis of some work that have been done in the Standards Committee because they were looking at ways of sharing the information and the Standards Committee as part of – we all know there is a lot of matrix work that goes on here, the PCAST report had come out in December 2010 and the Standards Committee had made recommendations for privacy metadata tags supporting that.

And the group in this data segmentation initiative looked at those recommendations as a potential means of sharing information and actually came up with something that was slightly different. So they needed to report that back to the Standards Committee.

They also have an executive summary document which was drafted by the community that explains the project and they have implementation guide test procedures. I won't go into details of the methodology, the technical methodology they developed except to say that they refer to it as being kind of a Russian doll concept where the tagging on the outside is neutral, kind of neutral so it will say you can share this with anybody it's restricted, non-restricted, restricted or very restricted. So, it does not disclose a medical condition on the outside of the envelope.

And then they used clinical privacy, the privacy metadata tag the uses of the standards to convey the confidentiality, the obligations of the receiving system and allowed purpose of use where the things that they looked at.

I apologize for this – the smallness of the type on this now that see it on the big screen but you should have a copy of this I hope to look at. And what they ended up actually were five pilots to test what they had worked on only one of which is really focused on federal sharing. The other four are private organizations, private companies that have agreed to work on this on their own.

And they are at various stages of their piloting. The pilot names include VA and SAMHSA, the Veterans Administration and the Substance Abuse Mental Health Services Administration, SATVA which is the Software and Technology Vendors Association, NETSMART, JERICHO in collaboration with the University of Texas and the Greater New Orleans Health Information Exchange.

Many of them are focusing on the federal aspects since those were focused on in the project itself but SATVA is also looking to test a New York State law as well because New York has some special restrictions on sharing HIV information. They are in various stages of this –

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**  
Joy?

**Joy Pritts, JD – Office of the National Coordinator**  
Yes?

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**  
And SATVA is the vendors association for mostly behavioral health vendors?

**Joy Pritts, JD – Office of the National Coordinator**

Yes, yes that is accurate. And they are working with HEALTHeLink which is the HIE for the Western District of – no I'm sorry I'm thinking of another project. We have too many pilots going on now, but they are working with HEALTHeLink for a pilot, which will exchange information beyond just the behavioral health care that will integrate information with primary care providers.

So, these are – they're using the technologies they're using include both Direct and Exchange and some are using break the glass technology. So you can see there is a wide variety of things happening. We expect these – all these are – as I said they started, some started before there was a presentation at HIMSS and some vendors I think were inspired by HIMSS and decided to join the club and test, and these will be taking place over the summer and we would expect for most of them that towards the end of the year we will have pilot test results that will be used to not only inform the implementation guide on this, but to identify what worked, what didn't work, hopefully we'll get a lot of lessons learned on workflow and things of that nature and we'd be happy to report back to you at that point.

In addition to the pilots that we've done we also did a crash course on mobile device security last year when we saw that the implementation of mobile devices in the healthcare sector was taking off at a disproportionate rate to the implementation of security measures.

And so we worked very closely with OCR and we now have a mobile device security resource center for providers and professionals on our website and one of the things that we have gotten very positive feedback on is that there are actual materials available for small providers to use online. So they can download fact sheets, posters, brochures, postcards things that they can post around their office to remind people that, you know, like don't leave that laptop there with 10 easy steps.

We took a very – we worked very hard with plain language specialists to try to get this at the appropriate level for the staff. And, you know, some of this is a real challenge when you're trying to get legalese into plain language but I think that we seemed to have hit a pretty right chord here.

We also did release our security video game which is an awareness tool. It is not meant to teach somebody every little thing about the security rule that they need to do. But we also – it became quite clear when – particularly when the meaningful use you must do a security risk analysis provision was highlighted that there were a lot of people out there that we thought, oh surely they use electronic health information, they've had electronic billing systems for years, never occurred to them that they actually had electronic health information honestly and that they needed to secure it.

And the requirement to do a risk analysis or that even was a security rule that was associated with HIPAA caught many people by surprise. The meaningful use requirement has been a wonderful eye-opener for a lot of people. And so recognizing that we have a lot of people who are at that awareness stage we focused on doing some awareness ourselves and the fun of the security video is when we show this to audiences you get this knowing laughter like yeah that goes on in my office all the time, you know, will you share your password, you know, can I take my laptop home even though it's not encrypted and things of that nature. So it really does focus on some of the main ways that we've heard that people are losing their information.

If we could get people to just do the things – in the small provider's office to do the things that were in the security video game I think we would be a big step – it would be a huge step forward. We don't want them to stop there though.

We also want them to read our guide to privacy and security of health information. And we had released this before our last update, but since then we have been working very hard to update this resource to reflect HITECH changes and this guide – we've gotten a lot of feedback on this guide. And the way it's designed is to help people, small providers again at different stages of implementation to know what they need to be thinking about privacy and security and so that will be updated. And we're also hoping to get away from that PDF format which is what we had originally hoped to do and to make it more interactive.

So, those are our major – we have many more things that we're working on but those are some of the major things that we've been doing since last fall.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thank you Joy. Hats off to the Privacy and Security Group 5 that recommend that we just draw attention to HIPAA as part of our Stage 1 that seems to have worked.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

That's right, right. All right open for questions. Judy Faulkner?

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Joy, what's the link to your video game?

**Joy Pritts, JD – Office of the National Coordinator**

I will get it for you. Can you – MacKenzie will send it out.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Okay, great.

**Gayle B. Harrell, MA – Florida State Representative**

Did we get this electronically? Because it will be on that if you'll make sure we get these electronically?

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

It was sent out this morning.

**Gayle B. Harrell, MA – Florida State Representative**

It was sent out this morning, it hasn't come in yet. I would very much like to look at that.

**Joy Pritts, JD – Office of the National Coordinator**

Yeah, it's at healthit.gov.

**Gayle B. Harrell, MA – Florida State Representative**

I have a few people I want to send that to.

**Joy Pritts, JD – Office of the National Coordinator**

We have whole mobile tab on mobile technology tab on our website now and it has a lot of – it has a security game – we have – it's on the providers tab I think but MacKenzie will send that out. And we have a lot of materials like that, the game. We're trying to get more interactive. We heard loud and clear from – we had a group of movers in and we heard loud and clear from them that they don't want to read PDFs. So, we're really trying to move away from that.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Any other questions? Very good. Thanks Joy.

**Joy Pritts, JD – Office of the National Coordinator**

Okay, thank you.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

We look forward to future updates. And finally, for the morning we have an update for round three from the Privacy and Security Tiger Team on their recommendations for health information exchange and query response.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Okay, yeah, we weren't sure whether the timing was going to work, excuse me, for Paul to be able to join so I'm going to fly solo on this one, but certainly, as is always the case we have, you know, quite the participation from a number of members of the Policy Committee on the Tiger Team as well as some from the Standards Committee, from NCVHS, etcetera. We always like to acknowledge them as we start.

This is the shortest presentation that we have ever given to you all which is nice, no it's two, well all right its four total if you count the title and the list of members. It is a continuation essentially of the discussion that we began at our last Policy Committee on policies for query for patient records and we were nearly done, but we had one question left that we were not able to complete as a Tiger Team and you all told us, go back and come back to us on this question and that is exactly what we're doing today.

You'll remember that when we tackled the query issue we had three scenarios that we were dealing with. Scenarios one and two dealt with targeted query where you know the provider who has the patient's record and you're seeking to query that provider or particular set of providers.

Scenario three involves non-targeted query where you know the patient, but you're not sure where the records are. So your first step is to try to find where the patient's records are. And we had a recommendation that you all approved about whether patients should have some meaningful choice about whether or not their information would be listed in a service that would enable their records to be located. We said yes, you agreed, that recommendation is done. We have it on the slide here only to sort of remind you of where we were when we left this conversation.

The question that we didn't have a chance to address previously but that we're coming back to you on now, is whether in this non-targeted query scenario where you're searching for the patient's record, should there be any sort of other limits on the query? Like a geographic limit for example or some other limit that might be necessary from a policy stand-point. Is there something about the notion of being able to potentially query anywhere that makes us uncomfortable and would cause us to want to put additional policies in place to limit that?

And essentially, we said, well we just got a lot of recommendations passed that are sort of very important to put some policy parameters around queries. Number one, we said that there ought to be meaningful choice about whether or not you are listed in some sort of aggregator service was the term we used that would enable your records to be found.

We also talked about having audit trails for queries, again, recommendations that you adopted. And we had a number of recommendations also on the – that were designed to give providers some reasonable assurance about the circumstances under which they could then respond to queries and disclosed records in accordance with their both legal and professional obligations.

So, given all of that, so assuming that those recommendations are in fact adopted we didn't see a policy need to layer on any additional policies at this time and so we recommend that at this time there need not be any additional policies even in this non-targeted query scenario.

We could decide to revisit the issue if some of the other recommendations that we have made as a committee are not adopted or we start to see an increase in nationwide query models and there are some policy issues that surface that we just aren't envisioning today because the fact of the matter is we don't have a lot of non-targeted query models today that operate on a nationwide basis. Many of them have been established by statewide HIEs or by vendors of their own network and so there is sort of some built in limitations that exist today.

We weren't trying to necessarily capitalize on those built in limitations but just to acknowledge that, you know, there may be additional policy issues that surface that we can't foresee, but today, given what we've already said we don't see a policy reason to create a limit on queries, you know, certainly, as part of meaningful choice would involve giving patients information about sort of what's the scope of who can query and the purposes for which it can be queried so that they can then make a decision about being listed in such a service.

So, it's a very long answer, but that's essentially what we said and that would essentially wrap up all our recommendations on query and then all of them would go in a single transmittal letter that would be easy for people to find.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Great. Farzad?

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Deven, I'm trying to I guess reverse engineer what the rationale would be that would trigger another look at it and let me see if this is the plausible storyline that if non-targeted – if there becomes established such a world whether through trust umbrellas or other approaches where a query from anywhere could go anywhere to, you know, query 300 million Americans records that there might be a risk of two things. One, you know, people who don't have a relationship but you already have recommendations around the querying should have a treatment relationship or not so that's not the issue.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Or B it could increase just because statistically because of numbers, it could increase false-positive associations. The bigger the pool the more likely you're going to have false positives, the more likely that you'll have inadvertent disclosures of, you know, someone else who is named Deven McGraw –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Who is not the person who is being chosen and this in a sense the fair information principle of, you know, minimum data and use limitation and so forth. Is that the idea?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, you know, I think you could envision sort of a scenario probably more like the latter, right, where because you're increasing the potential records that could be exposed in the search that the number of false-positives might go up. On the other hand, we have recommendations on matching that, you know, require, you know, each entity to pay attention to matching rates.

I mean, ultimately we're depending very much on the sources to evaluate a query that comes in and do their best to match it with the right patient record and if that requires additional information in the query in order to narrow down the number of records then so be it.

But we had recommendations on matching that we thought were appropriate to address that scenario and it wouldn't cause us to say, well, we think they're ought to be a geographic limit on queries, right? I mean mostly we were worried about creating a limitation that didn't match up with a clear policy need that might end up limiting exchange because we've said well you can only search in your state or you can only search within a 500 mile radius of where the patient shows up for care, you know, on the theory that most people get care locally but not all the time.

And so we didn't, again, absent sort of a clear policy issue that we didn't feel we had already addressed, that we thought needed to be addressed it just sort of felt maybe premature to layer more in at this time but we reserved the right to sort of monitor where the situation is going and to see when we do – you know, when there appear to be questions that are coming up that we need to resolve or if there were recommendations that we put forward that didn't get adopted where we thought that there was a piece that was missing.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, I have another exemplar to test the policy.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Okay.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, if you look at where the violations occur, they basically occur with publically visible folks, they could be VIPs or they could be like the bombing suspects.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**  
Right.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

And the other places is employees, you know, staff.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**  
Right.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, those are the two common violations. In those cases you can imagine that – so somebody has seen one of the bombing suspects when he went to school somewhere and just did this open non-targeted query, is that a stimulus for some kind of policy limitation?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

So, in each of those cases somebody is doing something they're not supposed to be doing.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

But that's what we're trying to guard against.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, exactly and there are policies in place to be guarding against that. We place a high degree of expectation on the part of the data holders to be policing the access of their users. I mean, you'll recall when we did the identity management issue with provider users, you know, we acknowledged that we have to rely very heavily on institutions, on physician practices to credential their users to oversee how they use the system, etcetera. We need to rely on that sort of I don't want to say house of cards, because – but it's sort of a pyramid approach to creating a trust environment and everyone has to play by the rules or in some ways it doesn't work.

And so we think that we should hold people accountable to those expectations rather than creating a set of limitations on the assumption that people will not do what we need them to do that could in fact create obstacles to the sharing of data for care because we're making assumptions that people won't do what they should be doing when in fact we have either made recommendations or we already have policies in place through HIPAA that require people in fact to do their jobs with respect to credentialing and to oversee the use of the system by staff to try to prevent that.

You know, we can have some further discussion about whether those problems would cause us to create some natural limitation – some additional limitation on queries. We didn't see the need for those in our own discussions but – in terms of how the Tiger Team approached this issue.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, let me go a little bit further on the thinking behind it. So, one the motor vehicle code said you should not drive at an unsafe speed.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**  
Right.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

It's a policy.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**  
Right.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Not everybody follows the rules so they have something called speed limits.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

As just a backup because you can't know that everybody will know what's unsafe speed. You carefully thought out scenario one and two, which gives people a lot of comfort.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, an organization says, look I know you we do business with you all the time and I know where you live and that gives a lot of comfort in the exchange. The concern would be if in scenario three, which is this broad scale, non-targeted query, you could be hurt by that – you might cause people to rethink strategy of scenario one and two, which is the most common thing that's going to happen and get more conservative there and so you might inadvertently cause tightening up in the most common scenario because the most common abuse is in scenario three and if we don't limit that at all then that could, you know, bleed over into scenario one and two.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah, I mean, it's an interesting question. I mean, I think the other thing to keep in mind is that at no point did we go to the place of saying that people would be, per se, required to release records, right? It is still the professional obligation of the data holder to make the decision to release consistent with their professional and legal obligations.

And so if there is a question on some of the scenarios that we went through in one and two, which you clearly remember, is this person who they say they are, do they actually have a treatment relationship with this patient, you know, we talked about things that would give you some reasonable assurance, but at the end of the day you still have to make the decision about whether to do that and all of that still holds true in this scenario too just because it's a non-targeted query doesn't mean that the record holder doesn't still have all of those same obligations to know that there is legal authority to send that record and we're counting on them to make those decisions consistent again with the professional obligation to do the right thing for the patient but also consistent with the law and when they're permitted to disclose.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

To drive safely.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

To drive safely, it's a terrible example because I'm like every other driver –

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

That's right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Because I think all of us can think of the time when we weren't necessarily compliant with that law all the time.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

That's human nature. Okay, Neil?

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

So, my memory is not as good as Paul's, so can we just walk through how this works for a minute? So somebody signs a consent where to say it's okay for non-targeted queries of my record. How does that happen?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, so in this scenario what you're consenting – what you'd be consenting to as a patient is to be listed in a record locator service or let's say we'll use the term used in the PCAST report a data element access.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

But where am I making that – where am I making that decision? And who am I telling about that decision?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, it depends on who is hosting the service. So, in the case of say it's a health information exchange that operates with a record locator service to enable records to be located you would – I mean, you know, depending on how they've created it sometimes the providers are the ones who get that consent, sometimes the consent comes through the HIE itself. There are different models in the country.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

So I'm just going to try to walk through this so I understand it. So the HIE that I'm working with is regional and I want to be able to be listed there but I don't want to be able to be listed – and I also want to be listed at a state level, but I don't travel outside of the state so I don't want to be listed outside of the state.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

So, am I going to be given the set of choices like how – you know, whether I want to be listed locally, statewide or nationally?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, we're not designing one way to do this Neil.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Okay.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

We're saying that if you're using a record locator service or some sort of service that enables you to locate a record of a patient where you don't know who her previous providers are that that service should give you meaningful choice about whether you're going to be listed in it. But that's just a one step. So, that's not then giving consent for you records to be released.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Right, no I've got that.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

It's just are you going to be listed in the service that will help find you –

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

In a non-targeted circumstance? And so the question that we still had on the table is whether – if you are going to operate a query service either you're a vendor and you're operating one or you're a health information exchange organization and you're operating one, you know, are you going to be required as a matter of policy to place some sort of limits on queries, by again, the other thing about this scenario, keep in mind, is that it's a query by a provider for treatment purposes. So it already has the sort of narrow confines of your finding a patient's record because you're treating that patient and you have a treatment relationship and you are a healthcare provider.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

So, to tie this into what Joy was saying before is there a way to segregate the different provider types that I might want to say you can query across the country for all of my medical records, but I don't want, you know, that does not include the time I was hospitalized in a mental institution or it doesn't include substance abuse providers that I went to. In other words there might be like a – I'm just thinking of an easy way to maybe exclude some of the complications of the segmentation if you could do something by provider type, you know, or abortion providers, or HIV providers or whatever so that there would be some way of identifying the provider types that we're allowing to be queried. I don't know whether that would be –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

I don't, I mean, we didn't dive into that in any detail because we sort of saw this, again, as a two-step process. One would be finding the record; two would be whether you have the authority to get the records from that provider in the first place. Having said that, we didn't dive into the issue of whether you would or could do gran –

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Granular.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Whether we would create some granular limitations around this initial query to find where the patient's record is. Assuming, you know, certainly in the meaningful choice process you would need to know sort of what all the parameters are of what you're agreeing to, right? What providers are included in this query, what are, you know, treatment purposes, what choices do you have –

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

And then it would really be up to the patient to decide. I do not think that that gets you out of –

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

No it doesn't.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

All of these issues that have perplexed us in the past in terms of sort of well what do you if the patient wants to make some granular choices but, you know, it's a reasonable question. We did not go there for this.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

I'm thinking of it more as a tool to get more people to consent to this non-targeted, you know, to be able to be listed as opposed to people thinking like, wow, well there is one thing I wouldn't want anybody to know and therefore I'm not going to participate in this at all.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

And that's kind of the –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

The all or nothing choice.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Yeah.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah, yes.

**Joy Pritts, JD – Office of the National Coordinator**

So, Neil we –

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

And then I'm done.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Okay.

**Joy Pritts, JD – Office of the National Coordinator**

This is Joy Pritts for those on the phone, we recognize that that is an issue and we have started looking at what we're calling data provenance. We're just looking at how you can mark information as to its source for the reason that you were explaining is so that it's a – when you look at granular choices you can have large degree, you know, by large categories or very small and so one of the things that we've been just starting to look at a little bit, do a landscape of seeing what's out there, what are people are doing in marking where the source of their data, how they mark the source of the data is one of the things we're looking at.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, Judy Faulkner?

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Yeah, if I understand this right, Deven, scenario three where it says may require use of an aggregator service doesn't mean that we're going to say aggregator services are going to be required, right? I'm trying to understand what that "may require" means, because some vendors and some vendor consortiums are getting together to provide that I think as either a service or as a business.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

But other vendors do it differently.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

And don't necessarily want or feel comfortable with and maybe worried about aggregator services for the same reasons that have been brought up here. So, I'm hoping that we're not going to go down the path of saying you have to use aggregator services. You don't see that happening, do you?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

It's certainly not what we said at this juncture.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Yeah, okay.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

I mean, it was, you know, what's – you know, it was really sort of us envisioning when you have a patient sitting in front of you where you don't know who her previous providers are –

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

If you have a mechanism for finding them.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Because scenario one and two in query was, well I know who this patient has seen and I can go right to them and I can ask.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Right, so I think you could –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

This is a scenario where you don't so it presupposes a circumstance where you might have way of looking for that patient's record.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

And here we thought that that triggered, you know, this set of conditions under which we said meaningful choice would apply at least with respect to whether or not you are listed in a service that helps your record be bound we thought you should have meaningful choice.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Yeah.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

And then that's when we got to the question of, well would we, you know, sort of place some sort of additional limits?

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

I think there are ways of looking for that patient's record that can be much more targeted that don't go nationwide because there could be a whole lot of Neil Calman's nationwide that would make it much more complex but if you're very targeted in where you're looking you can be more accurate in making sure it is the correct Neil Calman and that it's what Neil wants.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah, I mean, there might be some scenario like 1.5 right or 2.5 where you have some idea where the patient's records are.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

But it's not, you know, completely unknown.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Exactly.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Where you're only doing a demographic search.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Right.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Gayle?

**Gayle B. Harrell, MA – Florida State Representative**

Thank you very much. I think for a lot of patients this is very problematic when you go into record locator services that are – without their totally understanding the implications of it and there is certainly an education component that patients need to know what happens when you have a record locator service. And I don't believe that patients – that there's enough knowledge out there at this point for patients to make that meaningful choice as to what the implications are when you are listed in a record locator service.

So, I think this is, you know – as these things are standing up we may see some real pushback or misuse of those kinds of entities. So, I think this is something that is going to be discussed for a long time. This is the first blush at it but I don't think the conversation is over on this.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

No.

**Gayle B. Harrell, MA – Florida State Representative**

On this aspect because this is where patients get very scared.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah, so I think, I mean, I think that's exactly why, you know, we struggled to come up with a reason why we would place any other additional limits at this time, but we wanted to specifically reserve the right to monitor and revisit this issue because there's just not a lot of experience with these models to date and it's sort of premature to confine them on the one hand, especially given all of the other recommendations that we made. On the other hand, you know, this isn't one where we sort of felt comfortable like "oh, we're done, we can go away and we'll never come back again to this issue" and hence why it's worded exactly as it is.

So, it might be able to be fine-tuned a bit on the language as I'm looking at it, we could give ourselves a more – to urge more proactive monitoring of how this develops to sort of see where we might need additional policy. Because I think we also don't really know all of the technical models that are going to arise in this space either to Judy's point.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, I might follow-up a little bit on what Neil and Gayle said. I mean, just it stimulated me to think a better way to word it –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Okay.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Because you talked about how we have policies in place, unfortunately that requires the trust be with the requestor and in scenarios one and two you generally know who the requestor is and that's generally the most prevalent kind of queries.

So, the goal, and I think Neil said this best, is we do not want the lack of something here to inadvertently harm the usual case. And Gayle has basically said and the big worry is not the usual case actually it's the unusual case, but it's the common case of abuse, the whole visible thing where they're just foraging.

The other thing that Neil said is this whole – deals with the granularity of restrictions and one way your first two scenarios worked is the patients had to tell you I was seen there please go get the information that's self-control –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yes.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Without even granularizing the data controls which was nice. I worry that not having any restrictions on this non-targeted blanket query almost defeats all of these almost built in efficient ways of both giving people real choice because they tell you where they would like you to have data pulled from and at this time if we don't say anything at this time we're essentially – well, one person's opinion is we're sort of disarming some of the other very strong recommendations you had.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, so here is the issue, if we don't answer this question at all, status quo, which is essentially what we have here.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

But that's not a good – I'm concerned that that's not a good thing compared to what you did so well with scenario one and two.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, I mean, this was intended to build on it. I guess what we're telling you is that we, at this time, don't see – don't have any other recommendations for you to address this issue because we were hard pressed to think of an additional one that we would layer on at this particular time.

Now, one option can be that the recommendations on query stop here and don't actually address the issue of whether there should be additional limits where we get to say, well, we have some concerns but at this particular time we don't have any other policy recommendations to make, but we should monitor it, keep an eye on it and not consider this issue to be done because this non-targeted scenario is the one that gives us, you know, a little bit of heartburn for all the reasons articulated. It just stops, right.

But the status quo is, you know, again, the stop gaps that we have are the recommendations we've already made and the ones that exist and have always existed which is at the end of the day it's the record holders decision – when to disclose.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

That's not true of scenario three though I don't think.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, yeah, no, no, no because scenario three is just talking about how you find a record okay? Once you know what provider you're defaulted back into the other scenarios, right? Scenario three doesn't give you auto access, it's just a way of finding where so that you can locate patient's record.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

I think part of what makes the discussion today a little choppy is we don't have the totality of the recommendations that this layers on top of here.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

And I believe what this layers on top of is the meaningful choice.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yes.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

And I think you can have discussions about how do you make sure that it is truly meaningful choice.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

And we've had a lot of previous guidance on that as well as the established treatment relationship or a patient having affirmative consent on the requester's side.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right, the audit trails, the –

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

So these are layering on top of some protections that we have already approved.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yes.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

But, we're not seeing here today.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

No, it's true and I'm wishing now that I had brought my backup slides.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yeah, Neil?

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Question for a minute? Just to – I think the best way to understand this would be to think about what we would say to a person at the point where they would be agreeing. So we would say to them that by participating in this a provider that you go to with whom you would have a treatment relationship with your consent would be able to look across the country and forever backwards to see whatever information might exist on you, but without your consent couldn't actually get that information. You would then have an opportunity to consent to pull down various pieces of that information or all of it, right?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, no, so –

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

So, describe what –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Although I think you overstated what we had envisioned at least in this scenario.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

So, could you say it the way you would say it to a patient? Because, I think that would help us understand like what it is somebody would be –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

I think – so I would say, would you like – so first of all if I'm putting together one of these lists, right, or I'm, you know, a provider saying, well, my vendor has this service that enables your basic information not – you know, largely demographic information to be listed so that your records can – so that somebody if you're in an emergency situation, for example, and they don't know that you see me as a healthcare provider or they don't know that you see all of these other healthcare providers can at least know who to ask for your records, right?

Because the record locator service is just where are they, where might these records be found not here's all the all records that we have on X, although given it just – you know, we've sort of envisioned this model where this is a step where you look for the records which means to actually to get the records creates a two -step process. So what you're asking that patient to consent to at this initial phase is "do you even want to be listed in a service that will at least provide pointers to where your records could be located?"

There would then be, you know, so the second step of querying these entities for your records, which, you know, would be up to that record holder about whether they would release it or not. Then you're in scenario one or two where you know where the patient's record is and you can ask the provider to provide that record at the time.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Okay, so they're at my office and I'm the primary care doctor and they say "yes, I want your record released to wherever I go and whatever – "

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah, you're compiling –

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

So, tomorrow they go to their –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

You're now compiling two decisions into one.

**Neil S. Calman, MD, ABFP, FAFP – The Institute for Family Health – President & Cofounder**

Okay.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

You're asking the patient for consent to release of records. This is just are you going to be in some sort of service that will enable your records to be found?

**Neil S. Calman, MD, ABFP, FAFP – The Institute for Family Health – President & Cofounder**

All records wherever you go, that's what I'm asking?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, no, I mean, it depends on what's the scope of the service. We don't have a national patient index. So, if you're in New York and, you know, you're deciding – you are participating in an HIE that has this service then the sort of terms of what records, what locations would be included would be dependent on what's covered by that particular service. So, you know, in some ways I think we're sort of getting wound up in the fact that we don't have a one-size-fits all model for this.

We have sort of assumed – we assumed a scenario three where you if you didn't know where the patient's records where this might be a way for you to at least locate the locations of where they were not necessarily getting the records and we said in that particular scenario that you ought to have some choice as a patient about whether you're in the phone book and then whether or not, you know, your additional locations can be queried for records once they're found taps you into other scenarios.

We don't have a single model for how this gets done. We don't have that much of this getting done to begin with, you know, we didn't see, as a team, the need to say, well, you should only be able to query in the state you're in, you may, in fact, only be able to query in the state you're in because that maybe the terms of darned service, right, it's not...but we didn't see at this point that there would be an additional policy that we would place on this.

But I will tell you that if we are silent on this they will still arise because, ultimately, we don't have laws – HIPAA doesn't say, well if you have a master patient index here is how you do it. HIPAA says to record holders you can disclose records to treating providers in a direct treatment relationship, in an indirect relationship, you can disclose records to payers depending on what state you're in, you might have to get authorization you might not but it's the point at which the disclosure of the record that gets regulated.

All this stuff about, you know, finding it, again, there might be PHI and here – I mean, here's always the other sort of rub is that when you list a patient and you also have a location for the record and you are disclosing PHI in that context you're just not disclosing a lot of detail. That's one of the reasons why we think there ought to be meaningful choice. But beyond that, you know, sort of whether we would at this time say you just can't do a query without some sort of limit given all of what we had said we thought for now, given the environment we're operating in and the plethora of models and the fact that there is not a lot of this stuff out there we don't have – they're naturally limited by geography many of them today because we don't have national lists, but –

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

So, Deven, if I may suggest a process point, I think you focused on the scenario three a very narrow question and I think what I'm hearing is the need for the Policy Committee members to see all the recommendations in context and that was your plan anyway is to now package these come back to –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, no we weren't coming back.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

No, you were just going to –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well –

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Because we approved the previous parts, right?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah, the previous parts were all approved. I mean, this is maybe a lesson don't come to you guys until we're all ready with the whole thing.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Well or a lesson in how we – what's the approval say.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Because you did describe scenario three from the start.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

And I think we are fine –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

You're building on it.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

With each of those and I'm not sure we've said, okay send those off to the National Coordinator, so I think we are sort of somewhat contingent on the package of three because you so nicely said, well, here's how to think about it.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Let me make sure that Art gets a chance to say something and then –

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

Yeah, so I agree with the first two scenarios that we have and I think this third one you're now presenting to us we need to kind of give some recommendation. I think it's valuable. I'm thinking about the case that might be the comatose patient comes to the ED, you know, you really don't have much. You might have an ID but that's it.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yes.

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

So, you know, I think this third scenario is one that would be helpful for that and I think that we should at least allow a query to happen at the geographic level, whatever that is, I don't know if it's state if it's, you know, there may be a lot of different things that that represents, but it would be valuable to have that available to the patient who presents unable to actually give permission.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

So, I don't think we should be silent on this, we should at least take an affirmative stance that this is something that should happen rather than saying it shouldn't happen at all, that's my opinion. Then the other group that I think about is the snowbirds, you know, the people who live in two places...

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah.

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

For part of the year and you don't really know what hospital they may have gone to but something happened in Phoenix and you need to know that and you would like to ask a question of, just like you said, the phone directory is an example of this, you know, how can you find something – you don't call up and say Deven McGraw United States, you say Deven McGraw in Phoenix, right, or Washington or –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Well, right. I mean, if you've got any information on me it's probably maybe hopefully something more than my name.

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

Right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

But maybe that's all you have. I mean, I'm perfectly fine, believe me, I don't think these question for the non-targeted situation are easy and I'm perfectly – I'm amenable to clearly addressing scenarios one and two, which folks were very comfortable with, and then trying to figure out a way to get at this non-targeted query situation in a more robust way over some time.

And we felt more of a pressing need to address the targeted query circumstance because of some ideas that were put on the table by the IE Workgroup for certification and the ability to sort of do queries using certified EHR technology and I think we were very successful and people were very comfortable with where we landed on those two scenarios, but this one, admittedly, is more prickly.

And, you know, we sort of got to the consent piece and then, you know, were really stymied at what else we could say because we wanted to address the issue of emergency situations where the patient isn't in her normal geographic area but all of the issues that you all have put on the table are all quite relevant.

The fact that a mere listing of a record being in a particular location is PHI and can, in some circumstances, be very sensitive. Do we want just to say, well, the patient said it was okay and so therefore that should be enough? That doesn't feel like it's sitting quite well with everybody and I understand why.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

I do want to bring the committee's attention however to the fact that we're providing policy or the Policy Committee by giving recommendations is providing guardrails.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

In the affirmative, when we affirmatively say these are what people should be doing is providing guardrails. If we're silent on it, it's not like anyone's asking permission –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

No.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Whether they can do it or not, people are doing it today and there are record locator services and there are local policies and trust communities, and governance, and those are happening today. So, us staying silent, I just want to – it's not like us staying silent on it –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Means it won't happen, right.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Right. All we've done is, you know, we haven't put an affirmative stamp on a particular set of policy guardrails. So, I would – if Deven the direction you were moving in was to say, let's take the two we've had and come back and see us, you know, I wouldn't drag it out very long.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Because, I think that we need to have policy guardrails around all forms of exchanges that are happening today.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

I think the challenge is that we want to make sure that guardrails aren't restrictions. And that's I think the problem that we're running into how do we visualize the future and figure out what is restrictive. I like the saying "sharing is caring" and when do we stop that caring wrongly because we confuse guardrails with being overly restrictive and I think that's the challenge in doing it.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

So, one thing that – so I think – so here's what I would propose to do is to dig into this scenario a little deeper maybe by reaching out to some clear examples of where this is happening either at the vendor level, at the state HIE level, other models, a few other models that we can think of so that we can get sort of a deeper understanding of the lay of the land that might more inform a set of policies that we would bring to you on this topic because I agree with Farzad it's not right or smart for us to just say nothing because in some respects it would be – we would be shirking the responsibility that we agreed to take on in trying to create some consistency around this issue.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Gayle and then we're going to break.

**Gayle B. Harrell, MA – Florida State Representative**

Yes, thank you, very much and Deven I totally agree with what you've just said. I think perhaps as a Tiger Team and a being member of a Tiger Team and unfortunately having missed part of that –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

That's okay.

**Gayle B. Harrell, MA – Florida State Representative**

I was in the middle of sessions so I did not participate in that conversation, actually, a big fight on Medicaid expansion. However, I think there's an opportunity here to challenge but also an opportunity perhaps you get a little more information about what's actually going on and if that means inviting more participants to our Tiger Team meetings to actually give us real life experience as to what is going on and how they are addressing the situation. What's the concerns they're hearing out there and particularly around the record locator services and what's going on.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yes, well that the key.

**Gayle B. Harrell, MA – Florida State Representative**

I think we need to bring more people to our table within the Tiger Team and have some open discussion on it so that perhaps there could be some finer turning of this. There is a great deal of concern about a location, you know, if you're in a behavioral health facility, if you are in a – if you've had an abortion, if it comes from Planned Parenthood or other, you know, facilities, there is significant information there within that demographic information, you know, sources that is – that patients become very concerned about.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Okay, yeah.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, let me try to summarize. We can take one of two actions and one of them is proposed by Deven. So, one action is to accept the non-new recommendations on scenario three and basically say, well then the job is done we have 1, 2 and 3 all packaged up.

And the other is I think what Deven is suggesting, which is a lot of feedback about not having any guardrails and so come back one more time with the whole package, the first two we've been comfortable with and how to deal with the feedback about the lack of guardrails and address it then. So, we either can vote on each of those or it sounds like the more consensus is to do the latter. Is that fair?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yes.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay. So, one more time –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

No, it's okay. I mean, I actually think is a very good result. You know, clearly, you'll see even in the way that we worded this that we were like –

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

You know, we're sort of – we were struggling a bit with what to do but acknowledging that this was –

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Right.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

A tough area, so, all right, well –

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Well, it's good to hear the feedback actually.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

I didn't even realize there was this much.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yeah, so those are further input.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yes, thank you.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thank you. Okay, so we can open it up for public comment, please?

**Public Comment**

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Operator, can you please open up the lines for public comment? And while we're waiting if there is anybody in the room that would like to make a public comment if you could please approach the table. I'll just remind everybody that public comments will be limited to 3 minutes and the committee is not required to provide a formal response. Thanks.

**Alan Merritt – Altarum Institute**

If you would like to make a public comment and you're listening via your computer speakers please dial 1-877-705-6006 and press \*1 or if you're listening via your telephone you may press \*1 at this time to be entered into the queue.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

And we do have one public comment in the room if you could please identify yourself?

**Maureen Boyle, PhD - Substance Abuse & Mental Health Services Administration**

Hi, so I'm Maureen Boyle, I'm the Health IT Team Lead at SAMSHA and, you know, so this discussion has been very relevant for our stakeholders today and, you know, I just wanted to basically highlight that, you know, these privacy concerns are really critical for behavioral health and making sure that behavioral health can be a part of integrated care and we recognize that data segmentation is an ongoing effort and is not complete and may not be ready for inclusion in Meaningful Use Stage 3.

But we just want to highlight that data segmentation is not critical for basic compliance with 42 CFR Part 2 and, you know, similar mental health and sensitive information privacy regulations. But there are certain things that, you know, we would ask the Policy Committee to look at in terms of the steps that we can take in Stage 3 that will both raise awareness among the general healthcare system about these regulations which I think, you know, most of the sector is somewhat unaware of specifically around the restrictions on the re-disclosure of information that, you know, for us is critical because behavioral health could, you know, implement all the systems they want and if the receiving systems don't have the capacity to control the re-disclosure of information we still don't have a system where behavior health can be fully integrated.

And so basically, I would just encourage the committee and the respective Tiger Teams to try and look at are there ways in Meaningful Use Stage 3 where we can really signal that, you know, these are important issues that are going to need to be addressed and, you know, in addition to the re-disclosure element.

The other one that I would add to that is the need for standards around how you communicate privacy policies. I think those are the two things that would get us to a place where you could have basic compliance with Part 2 and make sure that behavior health is included.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thank you and I believe we have one public comment on the phone?

**Deborah C. Peel, MD – Patient Privacy Rights – Founder**

Hello?

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Yes, you are there, could you please identify yourself?

**Deborah C. Peel, MD – Patient Privacy Rights – Founder**

Yes, this is Dr. Deborah Peel with Patient Privacy Rights. Yes, I wanted to comment a little bit about the data for segmentation pilots in some of the discussions today. First of all, we're very concerned with whether the data for segmentation pilots are going to be carried out and whether this is really going to be part of health in exchange. Hello?

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

We hear you.

**Deborah C. Peel, MD – Patient Privacy Rights – Founder**

Oh, okay and that's not been clear to us that they're going to be funded at this time. We think it's critical because really people have these rights to segment data.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Is that the conclusion of your comment?

**Deborah C. Peel, MD – Patient Privacy Rights – Founder**

No, I was hoping for an answer.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

The committee is not required to provide any answers it's just a public comment time.

**Deborah C. Peel, MD – Patient Privacy Rights – Founder**

Okay.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

If you want we can try – if you want to send me an e-mail I can try and follow up with you separately.

**Deborah C. Peel, MD – Patient Privacy Rights – Founder**

Okay, well, I guess the other thing that I have to say is segmentation technologies do exist, they have been in use for over 10 years and they've been in use widely in mental health and addiction treatment and so, you know, again, the new standards and so forth are great, but the idea that this technology doesn't exist and isn't ready is simply wrong.

Further, I understand that most electronic health records are capable of segmenting erroneous information. And again, if the technology exists to prevent erroneous information from being forwarded, as a matter of patient safety, that same kind of functionality could be used to prevent other kinds of sensitive information from being forwarded and disclosed which was in concert with what patient's wish and their rights are to restrict the flows of certain sensitive information.

And so, I think that I particularly want to highlight the fact that, you know, Judy Faulkner continues to talk about how these technologies are too difficult or too impossible and the problems are really not matters of technology. The technology certainly has some cost and some difficulty and there are many ways to do this but the public truly expects these technologies. It's been a matter of law. The people have a right to control certain kinds of sensitive health information for a very long time and these laws are still on the books of most states.

And so we really think it's critical that this committee asks industry at last to begin to build the kind of systems that people will trust and need to be willing to disclose sensitive information and even seek treatment in the first place.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thank you very much. That's the conclusion of your three minutes for the public comment. There is a second public comment portion later on in the day if you want to provide additional comments. Are there any other public comments either on the phone or in the room?

**Alan Merritt – Altarum Institute**

We have no public comments.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Okay with that I can hear lunch outside, Paul.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yes, thank you very much. I think we had really a good and hearty discussion on both these two major topics one on the workforce education and training and the other on non-targeted queries both of which I think will benefit Workgroups in looking at it, deliberating further and returning with their recommendations. MacKenzie do you know if John has – if we delayed it by 5 minutes will that impact his schedule?

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

I'll reach out to him during lunch. I believe he had a little bit of time before and after.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, great, so we'll reconvene at 1:20 then please, after lunch.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

If everyone can please take their seats we'll get started in another minute. Okay, operator can you please open the lines?

**Operator**

All lines are bridged.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Thank you; welcome back from lunch everybody I'll turn the agenda back over to Paul Tang.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thank you, MacKenzie and John must be on the line?

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

I am indeed.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thank you, John. So we returned from lunch and we're going to hear from John Halamka who is one of the Co-Chairs of the HIT Standards Committee, our sister committee, who anoints and motivates standards to be developed and harmonizes them, but at any rate, John has some feedback from the Standards Committee some of which impacts the requests made from this committee and an update on some of the work going on there. Go ahead, John, thanks.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Great, well thanks everybody and as the Standards Committee formulated its work plan which attempts to mirror your plan there were several scope questions to the discussion and Doug Fridsma and others thought it best that I bring them to you directly. So, Paul, I'm not sure you're going to answer every one of these today, but maybe we can tee them up and engage in a robust discussion and hopefully get some clarity today and with additional meetings of your group.

So, let me start off with, as Doug Fridsma, originally in February produced the work plan for the group, he lists several tasks and we have done our own refinement of those tasks but let me start with the first, additional standards to support the transport of data to and from patients. So, what we are seeking here is clarity. Do you mean just as with summary transfers of care an object a transfer summary, a payload is sent from one place to another from an EHR to in this case a PHR for the patient or are you referring more to a website that a patient can go to and download their record. You know, what precisely does it mean to support transport of data to and from patients? So, Paul, do you want to just open it up for comment on that one?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Actually, I think I'll start that one, I think it's the former, because this was part of the transmit.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

And, so, I the patient am using a third-party PHR product either web-based or on my smart phone and a payload comes in from an EHR and transfers that document that standard summary of my care into my application?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

It's part of the T of VDT, so view, download and transmit.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Okay.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

And the transmit Queen just walked in which is Christine Bechtel.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

So, hey, Christine, so the question again is additional standards to support transport of data to and from patients where the Standards Committee could envision that as a payload going from one place to another permanently or the standards that might permit patients to enter data in a webpage and then press a button and have that go back into the EHR and the notion of download from a webpage or upload in a webpage versus actually packages of data going over the network as transfer of care summaries today are part of Meaningful Use Stage 2 going from provider to provider are really different kinds of standards?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

We are focusing I think on your first articulation which is to transmit a package from the EHR to someplace else that can make use of it for the patient.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

John, maybe another way to put it is, is there anything additional that will be needed to help patients participate as fully as possible in the ecosystem of information exchange where providers to providers can use the protocols but if a patient says "send my information there" are the standards in place to indicate this came from provider A is going to location B or provider B on behalf of the patient, motivated by the patient for example.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Sure.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

There may have been some, you know, force fits or kludges done to accomplish that today and is there anything more that could be done to explicitly recognize the role of patients as participants in information exchange?

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Sure and this is fair and recognize the Direct standards certainly would enable a provider to transport a package to a patient. At HIMSS, working with ONC, Beth Israel Deaconess showed how a patient could register for care in our clinical information system and then we would push the transfer of care summary both to the primary care provider and to the Direct address of the patient's choice in an application neutral kind of way. So, I think it's, Farzad and Paul, that's really the use case you're getting at and then as you say transmit additional to let's say a patient steward of data and go to this third-party from here.

So, the second question and this one I bet is going to be more challenging for you to answer. Standards to support image exchange. So, we really need a use case or two to help us with that because there are so many kinds of image exchange.

I want to grant access of my images to a doctor in the emergency department to view. A hospital wants to send images instead of a CD to another hospital. There are cloud solutions, there are what I'll call PAC system to PAC system solutions, there are third-party companies that translate data into a web friendly format along the way and so we just weren't quite sure if you had use cases in mind for the kinds of image exchange that you envisioned.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Or number two, which is instead of the CD to be able to exchange images from one system to another, you might have had the other things in door number three and four, but I think it was door number two.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Okay.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Christine wants to add something.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

Sure, hi John it's Christine Bechtel. I think we were talking in terms of use cases. We had a discussion last week of the meaningful use subgroup on Patient and Family Engagement and we had put a question out in the RFC around patient access to images and the idea was, you know, that if you made images be able to be delivered to patients as well through whatever mechanism then perhaps that would facilitate not only engagement but also, you know, reducing cost, right? Because, I remember I had that test done and here it is.

And I think the challenge that, you know, so I can share it with the provider. The challenge that was raised though to us was well, you know, you don't want to let patients have Direct access to a PAC system because then if you give them access to your PAC system what else could they do while they're in there.

Another challenge that we heard was, well if you give them a link to an image it's not going to be as useful for, let's say, the next provider down the road because it won't be the resolution quality, you know, required for diagnostics, etcetera. So, I personally am not either clinical or technical enough to know how to navigate that but the idea of a simple use case that says, gee, what's the best way to give patients and family's access to images would be helpful. Some guidance on that would be helpful.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Right and so Christine exactly to your point there are different kinds of images, diagnostic quality images, those that are appropriate for secondary review, those for which the patients simply want to show their other family members to illustrate the nature of their problem and so DICOM is a sometimes extraordinarily information dense and very large payload but of very high quality as opposed to, oh, I'll convert it to a JPEG and that way we can kind of see what's going on but not at a level of granularity.

And so to your point, you know, is it patient as data steward in the transport of a very high quality payload from hospital A to hospital B is it the patient able to look at a webpage and say "here's my broken arm take a look at that" and it sounds to me like it's more the patient eliminating the CD and steward of transport than so much it is viewing the broken arm with family matters for interest.

**Christine Bechtel, MA – Vice President – National Partnership for Women & Families**

I think that's probably right. I think we were hoping that there could be some kind of, you know, benefit in the cost reduction side through avoiding repeat tests if I, as a patient, could be the, you know, data exchange of one and moving it to other providers, but I think that raises the issues that, you know, you've confirmed around, well what's useful to providers and then is that even doable with images that are very large and take up an enormous amount of bandwidth and I don't know the answer to those.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, let me try to expand on what Christine said. So, like in photo processing software you can export in various levels of granularity of resolution. So, in some sense the two scenarios that you mentioned are of interest to us, one is the DICOM, the image reading professional and the other is the low resolution one that either the patient or frankly the PCP would be happy with and it would be nice to have that kind of capability. And I have Neil and Judy.

**Neil S. Calman, MD, ABFP, FFAFP – The Institute for Family Health – President & Cofounder**

I just want to say, we can't give up on the high resolution image and the ability for those things to be transported because we've made a promise to the country that we're going to reduce duplication and if somebody is going to use somebody else's CT or MRI they're going to need to see it at a level of resolution that, you know, somebody can read it and make use of it. But, I do think that to make it flow to primary care providers, to other people that will use it there should be a low resolution sort of option but we can't give up on the first.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Judy Faulkner?

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Should we be thinking of different technologies in other words when we use a link to the Internet we don't copy everything from the Internet every time we want to look at it. And should we be instead working on how do we link to those images rather than how do we move the images. I think that's one thing. The second thing is I know in Sweden I was there and met some folks who are doing some clever stuff on moving detailed images over with very low –

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

– low bandwidth.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Yeah, whatever it is, yeah. They're compressing it in ways that are really good. So, I worry, not worry that's not the right word, I think we should be looking outside the box on this one.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Right and Judy what you've outlined is exactly the kind of question we had, because, as I say in architecting this one way is move the giant highly detailed object to a patient's personal health record where it can then be moved elsewhere or leave it in place but pass metadata around its location so that the patient could say "hey, here is a URL and a secure login to the place my high resolution image exists and, oh, doctor not only can you view it, but if you chose, you could download the original DICOM object if it was of use to you or something of that nature.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

John, does that approach re-duplicate all of the policy challenges around query? Because one of the powers of the consumer mediated information exchange use case is that by exercising their HIPAA rights patients can be the medium for information exchange without requiring business-to-business, trust agreements and the like.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

And so for example I was at a cloud provider this morning that specializes in image exchange and the notion was you really don't need business-to-business you simply are providing the patient via the Direct protocol a pointer, a URL, to the image and then the patient could pass that off to others. So, that's one possibility.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Although you do rely on the stability of the pointer, the record locator, whatever it is the intermediaries that get you there and will that be –

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Correct. Okay, well, I think you've framed up very well the issues there and so I know what to tell the group. As, I go through some of these others I don't think we have necessarily detailed questions for you, but I'll just ask some advice.

We do see the need to represent a genomic data in the EHR and I don't suppose anybody on the Policy Committee has decided should we store the whole genome, the biomarkers, some specific subset that is going to be of clinical relevance, probabilities disease, does anyone know from a genomic stand-point what it is you want us to store?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Was that you?

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

We had some of I think –

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

I'm quite positive we didn't direct this.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

We had talked previously about, I don't know what the data needs necessarily are, but we had talked previously about linking genomic data to clinical decision support to identify high-risk propensities for disease and things like that but we hadn't talked about storing like the entire genome or – it's in the RFC though we could go back and look at it.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

I guess, John, the question of how the genotype and the phenotype come together is one that is an important issue and there's been some movement on the research community side and part of the question is if we can help and if so, how to have some standardization on that. And one response is you just focus on the phenotype folks on the EMR side don't worry about the genotype. Genotype, genotypic and genomic information isn't going to in the EHR it's going to be somewhere else and, you know, there are – the community that deals with those whether it's whole genome sequencing approaches or more of the specific mutation typing we'll figure that out.

And I think the committee's question was for example, again, if we take the personal consumer mediated exchange use case, which is very helpful in these cases, right, and say, if I wanted to download into my personal health exchange my genomic information what are the standards that are currently – might make sense either on the two main approaches to storing genetic genomic information.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Right and so in my personal genome for example my 750 mgs of 3 billion base pairs is available for download as is structured interpretations with the mutations identified, the probability that those will affect a disease state and the severity of the disease state should it be expressed. So, I guess, you know, final question is, do you want us to explore, given that there are different use cases, both those kinds of possibilities?

**Madhulika Agarwal, MD, MPH – Department of Veterans Affairs**

Yeah, so this is Madhulika Agarwal, you know, Farzad certainly there are research projects that are currently underway. I know in the VA we have a million veteran program that is collecting information and it's an IRB approved study to collect this information with a very aspirational goal of about 1 million folks.

And at some point, I think the interest is going to be in getting this information away from the separate database into the electronic health record so that the genotypic information and the phenotypic information can be used for further studies or at maybe some point with some very precise or precision medicine.

I think that conversation is important and probably should begin now because I'm not sure that we are the only people who are doing this. I'm sure there are many others who are likely very interested in forming these sorts of groups. So, I think earlier is better is what I'm getting at.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Very good.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

The other question I have John, it's Deven, is that this – as a topic it's being presented as one that falls in the security area as opposed to the – because it says standards for, unless I'm reading in the wrong place, oh, you're up above this. I'm looking at standards for securing data at REST, never mind.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

But, since Deven has asked the question that is the next topic, which is Deven, per the HIPAA omnibus rule, which I'm sure you know all 563 pages, should a provider hand off to a patient their genomic information and the patient keeps it on their personal device is there a need to secure that meaning that is the provider still responsible for it? Is it now in the hands of the patient, the patient can do with it what they please? Should the folks on the Standards Committee provide a meaningful use standard when in fact it's a handoff to the patient and in effect it's already been released to them and is in their custody?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Right, I mean, you're right that that hand off to the patient takes HIPAA and the omnibus rule and any other associated provisions under HIPAA really out of the equation. I mean, the transport mechanism for getting it to the patient typically has to be secure unless the patient says send it to me in this way and this is how I want it. And then once the patient has it it's really up to them. So, then in terms of allowing patients to then be able to share that data with healthcare providers and have that data be consumable by the EHR your back up into the bucket you were just talking about I think.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Great. So, moving onto the next page and this probably, for Judy Faulkner, would be a very salient comment. The C-CDA is really an episode of a care standard. It is not really a lifetime medical record standard nor really was it ever intended to be a bulk record sharing standard. And, so we actually are going to reword this to say, choose appropriate standards so that a lifetime medical record may be transmitted from one EHR to another EHR or many medical records might be transmitted from one EHR to another EHR. That's I think what is also our understanding of what is desirable from a policy perspective.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yes, correct.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Now the next one is advance directives care preferences. There were two ways we could think of this. Do we want an indicator that says an advance directive exists? Do we want a pointer to some other place where care preferences or an advance directive exists? Or are we looking at inventing the standards by which DNR, DNI, pressors, care preferences in a structured manner could be recorded within the EHR itself?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

It sounds like I think the most useful thing would be, well, is all the above. But don't you need number three, before you make – doesn't number three have to be in place so that access to these directives wherever they are become more useful or at least more meaningful to the computer and consequently more useful to the providers? Gayle?

**Gayle B. Harrell, MA – Florida State Representative**

Yeah, and I also want to make a comment that. DNRs are sometimes state specific. We have a very specific state requirement given some political situations in Florida in the past that are – you know, would be different perhaps than New York or California, or Denver, you know so don't want to get too specific in those standards because they may not be the same across the nation.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, John, I think we are interested in ways to make this available to the people who need it at the time its needed and that would certainly be, you know, number one and two. And to help make sure that the folks are reminded – Farzad's initial 5 percent, it's useful for the machine to understand it too. It won't – I mean, clearly it would be helpful if the machine understood it in the context of state laws even.

But, so I guess I'll take it back that I don't know that we have to do three first, but I think we need to get the information, the relevant information to people who need at the right time which is one and I think two, and then be working on in parallel a way for us to bring – for the machine to help get it to the right people at the right time.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

And so I reflect on my father's recent passing where I was carrying his advance directive, the Durable Power-of-Attorney, the healthcare proxy as pieces of paper with me and it would be useful to mark an electronic record "son is hand carrying these documents around" so that folks who would be at the bedside making clinical decisions would know that such things existed at various entities.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Well, I do think that there are two issues that maybe we're conflating. The first is, what is the concept and the second is, is it structured, you know, as data an machine interpretable or not and I guess the question for Gayle in this context would be, is the fact that there are state variations in what the – how it's asked or what the data elements are, does that have implications therefore for not having the indication itself be part of an EHR even it's as a text blob or does it have implications that we can't standardize the data elements within that concept?

**Gayle B. Harrell, MA – Florida State Representative**

I think it's the latter.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Okay.

**Gayle B. Harrell, MA – Florida State Representative**

Because you certainly would want to know that one exists and you would want to know if it's available where it is and if there's a way to do it as a PDF file or text file within the record that would be extremely helpful. But you have to be very specific about the data elements because they vary from state to state and some states have very complex requirements, some states have essentially minimal requirements.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

So, John, reflecting then in your example, there may be not just an indication but the ability for the system to retrieve that whether it's scanned or otherwise indication?

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Great, so very, very helpful. So, one last item for you and this is actually in some ways related to this discussion we've just had with advance directives and that is care plans in general, care team in general. Same sort of question there is, as we reflect on the standards that we would need for such a thing is it a care plan exists, a pointer to a care plan, a free text blob of the care plan, a structured set of data elements, which described the care plan, desired outcomes, care preferences, what does it mean to provide standards for care plans and care team?

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Could I ask you, John, in Stage 2 how far did we get? It was something about how it has to include three elements of what the goal is?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Patient goals and instructions.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

And instructions.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

Instructions and care team member lists.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Right but it was unstructured, that is to say it was free text.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, in a sense that's what motivated the question is in a sense it's turning the question around back to you. What can we do now to move this topic along? Is there a definition of a care plan, one period? Two, that people understand? And I think we got actually some feedback last month from ONC that neither exists. So, we are looking for what we can take advantage of now and then what might be in the pipeline and Christine has something.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

In terms of the way you asked the, John, some of the possibilities mentioned would be going backwards. So, we're not going backwards. The question is given this is where we landed on Stage 2 are there any ways in which we know enough about whether it's certain categories or classes of care plans, whether I don't know future orders or future encounters, intended prescriptions or whatever, some category could be leveraged to make it more structured is the way I understood it.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

Hi, John, it's Christine, I would say that the, I know Leslie Kelly Hall was chairing the Consumer Technology Workgroup and I think they're beginning to look at care plans and standards for them. We did work back when we were trying to think through what Stage 2 could look like for care plans, I think it was George Hripcsak and me, and a couple of others, I think Charlene as well and what we found was no there is no single definition or template or anything for a care plan which is, you know, a challenge in and of itself.

We've since I think discovered a couple of things. One is the sharedcareplan.org is the website, they built a quite good care planning tool that's a little more in depth and would really connect nicely with some of the data elements in view, download, transmit. And it's a really, I think, a very good, very patient and family centered representation that you might look at. I think it's proprietary though so that's sort of interesting but you can at least see the template.

The second thing is, because of this challenge about 20 or so consumer organizations pulled together a set of principles around what care planning would mean for them and it was really, and I'll share those with you, but it was really built off of the discussion we had in meaningful user around this idea of a collaborative care platform or a whiteboard.

Because we came to the conclusion, I think in the Meaningful Use Workgroup and in Care Coordination Subgroup that it shouldn't be thought of as a document anymore. It's not a plan, you know, in the sense of a very static thing but rather something that is a little bit more dynamic that has some common data elements but also has some functionality to be updated so the patient can contribute, you know, reports against it as well could the provider and it's much more of a dynamic interactive platform. So, I'll share with you some of the materials on that. Can I come back to the advance directive thing for second? I'm getting ahead.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

Thank you. So, one – just to kind of add one thing to that. I totally understand the challenge with different state laws. We were going to have a listening session on that and I'd like to raise that again and say that we keep coming back to it and saying we really need to understand more and so I think there is some urgency around having a listening session around advance directives because in the end it's good for – I think and in the short-term if we can get to a place very quickly that says, you know, location of advance directive is "son's briefcase" that's great and is certainly better, but I think at the end of the day we also want decision support connected to the content of an advance directive which is hard to do I think without structured data.

I mean, we hear many reports where, and I know it's been the case in my own family too, where the healthcare providers are busy and lots going on and they missed a part and they resuscitate when they're not supposed to or the opposite, you know, so we want to actually link it to the kind of decision support and changes in workflow that would help honor the patient's own preferences. So, I think if that's, you know, an endpoint goal then if there are some common data elements that we could establish in a shorter term as structured data to facilitate that, it would be really important, but I think we have to have a listening session to know that.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Great –

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

And one of the ideas that we had when we discussed this was POLST, because those are written as executable orders so that's a much more discreet way and I know it's not standardized now, but the question is can it be standardized so that those orders contained in a POLST can go from one EHR to another, that would be a way of transmitting that.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Well, once last question of intent and I think Farzad you've already answered this it's probably redundant, but when you asked for PSO reporting of defects is it the intent that the certified EHR technology itself would include a mechanism for gathering defect information, packaging it into a standard vocabulary and transmitting it to a PSO using a common format?

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

I think similar to the structured data capture discussion there may be secondary use of some information and the ability to supplement that with information that is not routinely collected within an electronic health record, but to be able to get into clinical workflows the ability to report adverse events and patient safety encounters of all types not just Health IT related through the workflow of the EHR.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Got it and the reason that I asked is I've highlighted in previous Standards Committee's I have an EHR, but I also have an incident reporting application which includes a very sophisticated ontology for describing events and whether that's an IT related event or a fall or a medication administration error but it's in many ways different kinds of data than the EHR itself would ever contain and hence the reason why we think common format is important and PSO reporting is really important as to whether or not the EHR is going to ever be the vehicle by which all that extra data is collected is really the question.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

John, is there a difference between the hospital context and the outpatient EP context where there is no incident reporting system probably in place?

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

And that would be true because in a clinician office typically you'll have practice management, you'll have EHR, you'll have productivity applications but you're not going to have this large suite of extra stuff like incident reporting.

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

In an integrated system though, as the one that I work in Denver Health, we use the same system both in hospital and in outpatient areas.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Right, I think this was similar issues arise when we're talking about public health reporting for example where often times the EHR was not what was used to do public health reporting there was a separate system, there is a separate workflow for having lab workers or infectious disease specialist identify those cases and report them and nonetheless those functionalities can now be certified as part of a suite of certified EHR technologies.

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

I think back to your point about the structured data capture it could be that the EHR tee's up a structured data capture mechanism that feeds a patient safety reporting system. So, you know, instead of, as John was describing, and in my institution as well where you have to kind of leave one application to go to the other.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Very good, well, hey, Paul, I have had my scope questions answered, so happy to entertain any other topics that you have, but I will certainly take these back to our Standards Committee Workgroups and get them worked on in the course of 2013.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

John, if I may while you are here, ask you to talk a little bit about how you're thinking of the API or data spigot concept and of what may be feasible. It's been raised many times as a key concern for example organizations that which to use third-party applications in conjunction with electronic health records of having access to their own data more readily and kind of the pro-innovation arguments around that. So, what may be, what are you thinking in terms of what may be feasible?

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Sure, so as you SMARt Project that is a SHARP grant funded at Harvard the intent is to create an App store for health and recognizing that the transactional interfaces that we have today may be very wonderful for the certain types of workflows where one application and another application are loosely coupled but in a very tightly coupled workflow where one needs rapid access to many data elements in both a read and write fashion using these kinds of transactional standards is probably not sufficient.

So, the hope, as you suggest, Farzad, is that an API would enable an App to be developed as an add on by any vendor to get access to medication and allergy information, to laboratory, and problem list information display it in novel ways and conceivably call an API which would allow a controlled and data integrity enforced right back for certain kinds of information, but this is being done at Harvard, it's being done with several vendor products and some home built products, but it is very, very novel and that is there aren't industry applications in production today that I can point to that have implemented the suite of functionality I've described, very good idea though it seems to me to have an App store for health.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

And John, could you describe not on the right part and you shared your concerns and were discussed in the Standards Committee but I think it may be useful for the Policy Committee to hear what may be feasible on the read part and maybe the examples you gave in your own setting work were illustrative.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Right, so imagine that a wonderful third-party product exists that contains a knowledge representation of all of the smart ways to order radiology test that could be built into the EHR or what if there was a straightforward API so that I'm in the middle of my order entry process and a third-party application has the capacity to receive data from my EHR which would be what is the nature of the test I'm ordering, a few basics about the patient and their problem and return in a mechanism that is human viewable the list of all of the things that are evidence-based that I should order and ordering one of them will result in an auto authorization at the payer of the test that I ordered.

So, in this way, the doctor has no clue that a third-party add-on application is being called but feels like they're getting some really wonderful functionality and its external to maybe the vendor's domain expertise to keep up thousands of radiology rules with all the current literature. So, in this way it allows this ecosystem we've been talking about of Apps to evolve and that's been in production at Beth Israel Deaconess for 5 years.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Good and Christine Bechtel has another question, John?

**Christine Bechtel, MA – Vice President – National Partnership for Women & Families**

Hi, John, we were meeting in the Patient and Family Engagement Subgroup of Meaningful Use last week and one of the questions that was included in the RFC was around radiation dosing. And it appeared to us that the feedback from the Standards Committee came back and said, yes there are standards that would support the collection and sharing of radiation dosing data with images I guess, but my Subgroup didn't believe it, so I want to ask about that and B I think we couldn't – we didn't know whether, even if there were standards does that require independent manual data entry or is it something that, you know, can be automatically included with imaging reports and then therefore, the concept of a use case if you will would be that through view, download and transmit if I can put all of my information in one place I might be able to calculate overtime how much radiation I've been exposed to from imaging?

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

And so I have had this in production at Beth Israel Deaconess for five years where in this decision-support system I just described there is also a display of the radiation dose associated with every test to be ordered, as well as there is an accumulated radiation of previous tests ordered displayed.

And, so let me do this because you've asked me a very detailed question, I don't, at the moment, know if those numbers were provided by the manufacturers of the devices, the American College of Radiology or input by radiologists at Beth Israel Deaconess. So, certainly it has been done and one hopes that it is something that is industry-standard but I will verify that for you.

**Christine Bechtel, MA – Vice President – National Partnership for Women & Families**

Okay, so, but what you're saying is it sounds like worst-case the dosing information was really entered one time and associated, you know, with multiple – I mean with that test so any time that test gets ordered –

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Right.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

You don't have to – okay, do it every time, that's awesome. And then the other thing would be I saw the patient generated health data including consumer devices is that where like the unique device identifier piece that we are hearing about would fall into place?

**John Halamka, MD, MS – Chief Information Officer – Harvard Medical School/Beth Israel Deaconess Medical Center**

And that is precisely correct, that is imagine that I have a device at home that is a Medtronic, very sophisticated, FDA, 5-10K approved device with wonderful data integrity and I have another device that is a Fitbit wouldn't it be useful for a consuming application to have some notion what is the device, what is the nature of the data and how much can I trust it? And so we have argued, and the FDA agrees, the UDI, this Universal Device Identifier, would be extraordinarily foundational for this kind of use case and we believe that the UDI should also be extended to consumer devices used for health.

**Christine Bechtel, MA – Vice President – National Partnership for Women & Families**

Thanks, John and I'll talk to you about moving up to Beth Israel Deaconess apparently soon.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Do you know whether UDI – so the UDI is being mandated for the device manufacturers but does someone regulate the recording of UDI by providers as they implant things or use things?

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Yeah and I believe the FDA does it for certain classes and the proposed rule is to now extend the scope of the number of devices with UDI but will clarify with my FDA colleagues for you.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay. Anything else? Judy Murphy?

**Judy Murphy, RN, FACMI, FHIMSS, FAAN – Office of the National Coordinator**

There are two more screens.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Were there anymore?

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

No, those were just our work plan items and the others were already clarified.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay. So, he was saying he only had questions on the ones that he –

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Can I ask something?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Sure.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

The standards which record – support record locator services and standards that support consent on a query response architect –

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Where – what report are you looking at?

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Oh, okay, so we will get them later on I guess.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Okay, thank you.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

Wonderful, well, Paul, thanks very much for the opportunity. I have some very good answers from you all and I will of course look forward to talking with you again as we make progress.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Well, thank you, John, thanks for asking the questions and hearing our response and thanks for all the work that the committee does.

**John Halamka, MD, MS – Harvard Medical School/Beth Israel Deaconess Medical Center**

All right, have a good day.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Take care now, bye-bye. Okay and so now we'll move on to ONC updates with – sorry?

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

And sorry, this is MacKenzie, I just wanted to switch the order Doug is offsite he had to call in so I want to make sure he's able to go first so if it's okay we'll just have Doug Fridsma go first.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Sure.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

So, if you can load his slides please? And Doug are you on the line?

**Doug Fridsma, MD, PhD, FACP, FACMI – Chief Science Officer & Director, Office of Science & Technology – Office of the National Coordinator for Health Information Technology**

I'm here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Wonderful, thanks Doug.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

The ONC update and Doug Fridsma is going to talk to us first and then Jodi.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

So, Doug, we're just waiting for your slides to be loaded up and just make sure you say next slide.

**Doug Fridsma, MD, PhD, FACP, FACMI – Office of Science & Technology – Office of the National Coordinator**

Okay, so while we're waiting for the slides to load up, so I thank you for the opportunity to present here. I think, in fact, John has done a better job I think of perhaps presenting a lot of the work that's going on with ONC, particularly in the standards area he's had an opportunity to kind of go through all the things that are on our list and I think we'll be organizing and trying to get a lot of this work together in the course of the next couple of months. So, do we have this first slide up now?

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Hold on, not yet. Yes.

**Doug Fridsma, MD, PhD, FACP, FACMI – Office of Science & Technology – Office of the National Coordinator**

We're just working backwards? There we go is that slide one?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yes we do.

**Doug Fridsma, MD, PhD, FACP, FACMI – Office of Science & Technology – Office of the National Coordinator**

Excellent so the first thing to say is that I would like to just give you an update on the participation that we've had from the volunteer community in terms of the S&I Framework. We've been going now just a little bit over 2 years, we've got 2200, almost 2300 people have registered on the wiki, there's about 700 people who have committed to active participation and ongoing calls. They represent about 538 different organizations and at this point we're closing in on 1500 working sessions held since the time that we started the work.

There have been – the pace at which this is going continues to be about 1 meeting every 3.5 hours and we've been at that pace really since the beginning so it's a tremendous commitment I think from the participants in the S&I Framework to really help accelerate and support the work that the HIT Policy Committee is doing in trying to find the standards that are going to be helpful.

We have received now over 3100 different HL7 ballots on those standards related to HL7. We still have some outstanding ballots that need to be resolved but every single ballot that we receive on every standard has to be resolved unanimously so it is a time consuming and challenging activity. Let's go to the next slide.

So, the S&I Framework has had about 17 initiatives that it has done since it began and we're right now in the process of kind of re-evaluating our portfolio and balancing them, if you will, in terms of the various activities that we've got going. There are a number of things that we've sort of listed as maintenance and maintenance doesn't mean that we're not actively engaged with it there are committee meetings that are not occurring but it's just a matter of us kind of moving to the next phase.

So transitions of care, for example, we're working very closely with HL7 and others to make sure that we've got the consolidated CDA properly supported so that implementers know how to do it correctly and if there are questions or – that arise we can then deal with those quickly. Laboratory results interfaces and data segmentation for privacy are also in that sort of phase where we're really trying to get it out, deployed, have it implemented and make sure that it's working properly.

There are three projects that right now we're sort of pulling back a little bit in terms of our active ongoing work not to say that they might not come back and help us. One is the certificate interoperability. We did some early work in the S&I Framework and provided some recommendations. Clearly, that's an active area of consideration with the Direct Project and others that use the certificates. Provider directories was an early topic that we covered and we probably need to revisit that at some point.

And one of the projects that just completed and we're getting our final reports on and we're trying to figure out what the next stage is, is on the Prescription Drug Management Program, that's still a high priority, we still have lots of work that needs to be done, but we've sort of put on hold a lot of those activities.

The remaining initiatives really are active and there's ongoing work that's going on with all of those. I'll try to briefly summarize those in the next slide.

So, this is our sort of classic diagram that sort of gives you an indication of where we are in the project and kind of what are the activities. The Direct Project, obviously, we're in production, we're still working out some of the implementation activities around the certificates and management there with our federal partners.

Transitions of care has completed the companion guide which really augments the implementation guide and provides better clarity for the use of the consolidated CDA within meaningful use. Laboratory results interfaces, we're working right now on making sure that if there are errors that we found that we can institute some of the – there.

The Query Health activities right now have – we have a number of pilots that are underway we're working very closely with the HQMF community that does quality work, because we really are thinking in terms of the quality improvement rather than just decision-support and quality measurement and so being able to do a distributed query using Query Health is something that needs to be linked into the quality assessment activities as well. That's likely going to take another look at the Query Health activities, particularly as we think about opening up the EHR and providing access to some of the information there in a standardized way or if we start talking about targeted query to be able to get specific information from a particular emergency room or clinic that you know that the patient was seen at.

The data segmentation for privacy had a great demonstration at HIMSS and it is right now in a series of pilots. We found that there has been a number of vendors that have actually picked it up and begun implementing that and we're working, even this week, within the HL7 community to make sure that we've got right ballots taken care of and that we can get the various transport standards that we have both web services, Direct and RESTful approaches to incorporate some of the principles of data segmentation.

The public health reporting activity, that community led project in collaboration with the CDC has identified a whole number of use cases that would be appropriate for public health reporting. But we're taking some of that work and now folding that into a specific line of work within the structured data capture initiative because much of the case report findings and things like that could be supported by creating a common way to have more granular data and assembling those to meet specific kinds of reporting requirements or investigations that the CDC might do.

esMD, although it hasn't progressed as far along the line there has actually been quite active. They've identified – this is a project that is in collaboration with CMS. Their principal goal is to begin moving away from paper-based and wet signatures to things that are going to be able to be supported using the standards that are coming out of the meaningful use activities.

So, one of their first barriers that they've worked on is to develop a specification for digital signatures that meets their requirements. And they are working not only across the signature for a package of documents, but also for documents themselves. And are also trying to figure out how they can go from that to segments within a document. So, for example, if you had a note that has a resident or an intern and then a co-signature with an attending physician being able to create those levels of specificity.

The longitudinal care coordination group has done a lot of work on care plans and so that's one of their principal use cases. I think the discussion that we've just have about care plans is something that we can begin to engage this committee. They are active and engaged and community led, and I think they would be delighted to share some of their experiences in working through the care plans and some of the data that the need to help support transitions into longitudinal care facilities and the like.

The laboratory orders interface was balloted back in January and we're currently in the reconciliation process going through all the negative votes and making sure that we've got everything handled effectively. And if you take the laboratory results interface, the laboratory orders interface and the eDOS, which is just sort of a list of the orderables, if you will, that all together creates three different standards that support electronic ordering, identifying the things that are possible to be ordered and then getting those results back electronically as well. And so as we finish up the ballots there, we'll be able to have sort of that the full 360, if you will, around laboratory test as well.

The Health eDecisions activities has been a very important project that's gone on and this is having two different use cases. The first is to share artifacts, knowledge artifacts, if you will, about clinical decision support. So, artifacts that are unambiguous and structure that could be ingested, if you will, by an electronic health record and used to help guide the development of clinical decision support rules or the like within those systems.

Use case two is really to be thought of as clinical decision support as a service. And the idea there is if you had a collection of information data that you would send to a service and say I have a patient who is a diabetic who has a hemoglobin A1c of this value and this is their current treatment regimen, you might get back then guidance about what would be the best next drug to do or whether there should be a change in their therapy. And so they're working right now in the use case and I think one of the things that's important about this is that that's actually going to start thinking about how to send and receive that information using the electronic health record.

We've done work on Blue Button Plus and this was our effort to try to take download, transmit and take elements from our portfolio of standards to help solve new problems and so this took the Blue Button, added Direct and a consolidated CDA and created an implementation guide that would allow you to meet the criteria of view, download, transmit and at the same time then be able to use and leverage the existing standards.

The most recent initiative that we've just launched is called structured data capture. They've completed their consensus. They're reviewing the final use cases and they hope to be able to start really working on standards development and harmonization in the course of this month. They've also done a review, a fairly comprehensive review of all the different people out there that support the kinds of use cases that help engage clinical research activities or patient safety reporting. And so now they're in the task of going through all that work and trying to decide what the right next step might be with regard to the standards that are there. Next slide, please.

We've got S&I Framework pilots all across the country. This is a just kind of a map that shows where they are located. We've got a number of different activities that are ongoing and it's such a critical part of engagement with the community to make sure that the things that are getting discussed and developed are actually piloted in the country so that we can figure out how to make sure that these are applicable in the real world. Next slide.

So, I just want to go through a couple of just highlights. I've talked a bit about these but just so that we don't forget any of those things. So, the structured data capture initiative is intended to develop a standards-based architecture so that we can supplement information that is accessible within the EHR with other data that might be important for that particular work purpose be it clinical researcher or quality reporting or the like and merge that together so that you've got – you can support those activities. Next slide.

This includes things like an electronic case report form. And so the patient centered outcomes research activities is something that really needs to be able to leverage the electronic health record and this is a way of doing that without creating so many data elements within an electronic health record that becomes unworkable in terms of being able to manage all of that.

Incident reporting for patient safety events using the AHRQ common format. Surveillance case reports for use in public health, for infectious diseases and potentially a collection of patient information used to determine coverage and this is a use case that CMS is interested in in terms of preauthorization for high cost items to see if there's a way that you could collect that information because it may not routinely be collected in the electronic health record but as part of the process of care you might be able to add some additional information into the electronic health record that would be able to support determination of coverage. Next slide.

So we've looked at all the concert series. These are the kinds of things that we've looked at, we've looked at CDISC and HIE profiles, the CIMI group that's an international group defining granular data, PROMIS, PCORI, USKIK, Duke there are some folks from the College of American of Pathology and so a whole host of folks have been able to present and talk about how they've handled this problem of capturing structured data in dynamic ways. Next slide.

So, within the public health reporting initiative they've reached consensus on the documents both on this framework and how they might be able use PHRI clinical document architecture lots of activities that are going on right now within HL7 around hospital acquired infections and also some other work that is going on within Atlanta here around organizations looking at what are the standards that are needed to help support public health and so we're working with them and really trying to focus a lot of the efforts to get these first building blocks done trying to figure out what the highly granular data elements might look like. Next slide.

Direct. We continue to push forward with making sure that we've got clarity around the Direct specifications. We've got a series of pilot communities that are working to develop what we call trust bundles ways that you can distribute certificates that say these are trusted certificates they've had the appropriate vetting that we'd like to see. So, the Western States Consortium, DirectTrust, ABBI have all looked at trying to create these trust bundles that then can be shared.

We're also working very closely with our federal partners to make sure that they have the ability to implement and use Direct specifications and of course there are challenges there just with some of the federal regulations and the requirements for privacy and security there, but we've been making tremendous progress and I'm sure that we'll be able to come up with a way of implementing Direct that gives us a path to make sure everybody can participate in Directed exchange. Next slide.

The laboratory orders initiatives, we've got only about 29 comments that need to be resolved. I'm hopeful that by the end of this week we'll be able to finish that so we can publish the implementation guide by June 15th. And one of the things that we have talked about before in the laboratory orders initiative is a really important example of this is that as part of releasing the balloted IG we've been working very closely with NIST so that the testing framework are released at the same time the implementation guides are so that this notion of a comprehensive implementation guide and standard includes the ways that you – not only the ways that you would implement it but also the ways that you test it.

And so laboratory orders initiative is our first at sort of following that new paradigm and data segmentation for privacy and use is the second that is also, in addition to publishing their implementation guide, has also published the testing frameworks as well so that we can do those at the same time. Next slide. Next slide.

Okay, so, I guess that is the end of the updates. I'm happy to answer any particular questions that people have, but we're working very diligently to try get all of the various pieces that we have within the standards and interoperability framework and within the SDOs at a sufficient level of maturity so that when the need arises we can tap into that and use that to help support some of the policy objectives.

And then also beginning to tee up some of the other activities that are coming down the pike to try to make sure that we execute on a query strategy that we have the ability to open up the APIs and the data so that we can get this ecosystem of interoperable electronic health records that we'd like to see.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Well, thanks, Doug. I can see it takes full-time just to keep up with everything that is going on, my goodness. So, because Doug has to leave any questions for Doug? Yes, go ahead Art.

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

Yes, Doug, thanks for the presentation. I had a question about Query Health. You know, in Stage 2 that they'll be specialized registries that providers or hospitals may report to and I wondered if there is a plan for how Query Health could apply to those types of specialized registries or has that been part of the thinking?

**Doug Fridsma, MD, PhD, FACP, FACMI – Office of Science & Technology – Office of the National Coordinator**

So, one of the things that we've done is looking at Query Health is to sort of step back and say again, what are the building blocks that we need to sort of have the ability to have, you know, big data analytics, databases that contain registries and things like that, but also to be able to support clinical workflows and to support what I call small data analytics. So, making sure that physicians also have access to their own information and can do the analytics and pick the best of breed if they want to do a particular kind of engagement around understanding their own data.

And, so I'm happy at some point to present to this group if you want to know a bit more about it, but if you think about this, what we first need is we need to have a way of asking a question of the electronic health record, you know, I need this kind of data and then getting back from the electronic health record in a standardized format the results of that question that you asked.

Now you should be able to just do it if you're the physician and it's your data and you could then take that information and do a mash up with other information, do some analytics, workflow modifications and things like that, but if you take that basic functionality and you layer on top of it an authorization, an authentication ability, you should be able to then do that kind of interaction remotely.

And, so whether it's an electronic health record or whether it's a registry, having a proper authentication and authorization, and the ability to move the query from one place to another that allows you to, in some sense, remotely ask a question and that helps support not only the registries but also would help support clinical care if you're trying to find a document that you know exists someplace else but you don't have copy of it.

And then the final phase is that if you wanted to ask a question remotely to lots of different electronic health records or registries, or other databases you'd like to be able to do it in a consistent way so that you don't have to have a specialized understanding of what data is in the electronic health record or that is in the registry.

And so there is work that's going on both within HL7 within the quality improvement groups, the Health eDecisions activities, and in the structured document working group in HL7 to try to figure out is there a way that you could come up with kind of an information model that described all of the elements that you could ask a question about and even though each electronic health record or registry might have a slightly different way of storing it internally, you could at least ask the question in a consistent way.

And so we have this notion of sort of, you know, basic query functionality, targeted query and distributed query and there's nothing about them that wouldn't suppose you could take out the standard that was used in the EHR but use that same standard in a registry or something else.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Doug, you mentioned the Health eDecisions. I know you didn't highlight it but just a couple of words for the Policy Committee about the Health eDecision Project.

**Doug Fridsma, MD, PhD, FACP, FACMI – Office of Science & Technology – Office of the National Coordinator**

So, Health eDecisions is a project that Jacob Reider and Alicia Morton have been sort of leading out of the Office of the Chief Medical Officer and we have been supporting within my office and it's intended really to try to create a way of exchanging information, knowledge information around clinical decision support as well as, that's their first use case.

And then the second use case is to see if something like clinical decision support as a service might be possible. There's a whole – my next sentence will actually contain no words it's just letters so VMR, QDM, HQMF and QRDA as well as HED are all the kinds of standards that we're looking at with that and what we're trying to do is make sure that we have reusable pieces in the quality space that can be used to formulate a clinical decision support rule for example.

And so alignment of the data models that support that, as well as, the kind of expression language, if you will, or the container that it would go in are work that's ongoing and it's a critical piece because if we really want to get to a world in which we have not just measurement but improvement we have to make sure that we bring those two communities together.

And so Jacob and his team have been doing really a tremendous job at bringing together these two communities that in the past have not done a lot of talking to each other and trying to make sure that they can share and have a common vision about how both measurement and improvement can happen.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

The reason I asked Doug is we started the day talking about quality improvement and process improvement and the HED decision-support is I think, and quality measurement portability, is going to be among the critical things needed for the following acronyms PCMH, ACO, MSSP, HBVP.

**Doug Fridsma, MD, PhD, FACP, FACMI – Office of Science & Technology – Office of the National Coordinator**

Okay, so I'll see your acronyms and raise you. So, one of the things that we're working on right now is that the way in which, in fact these are the discussions that are ongoing this week, one of the challenges that we have is that trying to make sure that we've got – we don't blend together two things that should be separated.

So, we've got things that describe the information model, things that describe kind of what a quality measure should be, but we haven't clearly pulled out that, you know, algebra, if you will, about how the data is assembled together to calculate the quality measure. It's kind of embedded within the HQMF standard.

And, so one of the challenges that we're working on right now is extracting that because I think if we don't do that it's going to be very difficult for us to reuse that calculus in both CDS as well as in the work that we've got with the quality measures.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, any other questions? Good, thank you Doug. And now we're going to hear from Jodi Daniel.

**Jodi Daniel, JD, MPH – Office of the National Coordinator**

Great, thank you and I will just note for the record that any time anybody complains about acronyms or citations we use in our Regs that I've never said an entire sentence just with letters. So, okay. So, I am just going to give you a couple of quick updates of some new things that have been coming down the pike in the last month. When we get to the conversation at the end of the meeting about things for next meetings if there are particular areas of interest folks have about ONC updates either for me to give a brief update to or for program leads to give an update to just let us know.

First I just want to start with some updates on the FACAs. So, first on the Policy Committee membership update. As you all know, we have members that are appointed by GAO, by members of the hill and some by HHS. We currently have eight slots on the Policy Committee that are appointed outside of HHS either by GAO or by members of Congress whose terms have just recently expired or will be expiring within the next month. Four of those slots are GAO slots; four of them are the Congressional slots.

We do not have – we are currently working actively with GAO and with the members of Congress to have those slots appointed, either reappointing the folks who are currently in them or naming new members. In the meantime, committee members are able to continue serving until their successor is appointed or until they are reappointed.

That said, I want to thank and recognize Scott White who is one of our four GAO appointed members that was mentioned who is one of the people whose term is expiring and who will be retiring from the Policy Committee. We thank him for his service and his hard work on the committee including the work on the workforce subgroup that we just heard today from Larry Wolf. He was our labor organization representative so we will be looking to GAO to appoint a new member for that slot and we will be requesting a letter of appreciation and certificate from the secretary for his service to the committee, so thank you to Scott White although he's not here we'll publically thank him for his hard work.

Second, I just want to note that we do have a new Workgroup that has been formed for the Policy Committee, I've mentioned this in the past that we were forming this Workgroup it's the FDASIA Workgroup, FDASIA is the statute that called on HHS to pull together stakeholders on a particular topic. So FDASIA is the FDA Safety Innovation Act, it was passed last summer and it called on the FDA to work with ONC and FCC, the Federal Communications Commission, to develop a risk-based report for framework for a risk-based regulatory approach for oversight of Health IT including mobile devices that both protect safety and promotes innovation.

The statute called – or enabled HHS to develop a Workgroup to get input from stakeholders on that and we have decided to form a Workgroup under the Policy Committee in order to get that feedback. We announced that committee on, I think it was, April 18<sup>th</sup> and we have had our first two Workgroup meetings the last two Mondays.

David Bates is the Chair of that Committee and Paul Tang also serves on that committee and will be Co-Chairing of the Subgroups of that Committee. So, those are two Policy Committee representatives that are on there. It is actually our largest Workgroup it's over 30 people including the federal representative from the three agencies. I will be serving on that as the federal representative as well.

The timing for this is really short. We've asked the workgroup to come up with draft recommendations for the Policy Committee in August and final recommendations in September. The reason for the tight timeframe is that we have asked – we've been asked by congress to have a draft report, to draft a report by January of 2014 and so that gives us very little time to actually take the recommendations draft it into a framework and get through the clearances we need in order to put that out.

We do anticipate that we will be putting that out as a draft for comments so that we can get broader stakeholder input as well once we do put together a framework. We expect the committee to give us input and recommendations into that framework not to develop the report itself, but to give us recommendations that we should consider in developing that framework and that report.

That Workgroup will have one in person meeting for a day and a half at the end of May, I think it's scheduled for the 30<sup>th</sup> and 31<sup>st</sup> in DC, it won't be a hearing it will actually just be an in person working meeting in order to kind of facilitate the discussion, like I said, it is a large group and we have a lot to tackle in a short period of time so we decided that it would be wise to have an in person meeting in order to get some resolution and consensus on some pretty tricky issues. So, we'll keep you all posted on that and like I said, we'll have draft recommendations with an opportunity for Policy Committee input and then final recommendations the following month.

Okay, so now I'll get to the actual ONC policy and programs update. So, just a list of some of the items to cover and I'll go through these pretty quickly. So, first, I just want to let folks know that ONC has recently updated our Health IT dashboard including adding Health IT Quick-Stats.

The Quick-Stats are concise and easy-to-understand, visual expressions of some useful data that are derived from ONC programs from our research and from the open government data set. So, for example, there are info-graphics on EHR adoption and use and these are designed to be easy to share via e-mail or social media so folks can use these and be able to reuse them as well in getting the message out to others. So, I think this is something worth checking out and for those who are interested in the data we've got some good visual representations that could be helpful.

Next, I wanted to mention we put out a governance framework for trusted electronic health information exchange. So, I'm personally excited about this. We've talked a lot in this committee about governance for health information exchange, as you all know, we put out our RFI, we got lots of feedback, we decided not to pursue regulations at this time but rather to try to leverage some of the existing activities that are going on, identify some best practices, do some monitoring.

But one thing that was also called on in the comments we received from the RFI was that it would be appropriate for ONC to set some policy framework, some general principles, some guidance for folks to align with as they are taking initiatives regarding electronic health information exchange in various regions, states and communities.

So we put out this governance framework and it's a set of principles. There are four categories for the principles. There are trust principles that are designed to focus on patient privacy, meaningful choice, data management, health information exchange and the like and they are based on recommendations that have come from this Policy Committee. So you will not be surprised when you look at these principles they will look very familiar to you all.

Second, there are business principles which focus on responsible financial and operational policies for governance entities with an emphasis on transparency and with a focus of patients – keeping the patient's best interest in mind.

The third area are technical principles which are priorities for the use of standards in order to support the trust in business principles and further interoperability and align with the standards that have come out of our regulatory process and our Health IT Standards Committee. And the fourth are organizational principles which are just generally applicable approaches for good self-governance. So, I encourage folks to take a look at this. This is up on our website.

What we hope is that this will provide a framework and a common foundation that can be applied to various different kinds of governance models that exist currently for health information exchange or for those that are developing. Some of them are things that are obvious and easy and probably every health information exchange and governance entity are already doing, some of them maybe a little bit more aspirational but are things that we think are really important that as folk are thinking about governance for health information exchange they should be working toward.

We do have the National Health Information Exchange Forum that NeHC has pulled together for ONC which have a variety of governance entities that are coming together to identify best practices, challenges, and share some of their learnings and we will encourage them to look at these principles as well in order to identify best practices that can align with these principles.

So, we're looking at this as sort of the North Star that we hope people are going to be kind of driving toward and thinking about how to get closer to these principles and align the work across the different activities that are going on nationwide.

Okay, next, so ONC is conducting the National Survey on Health Information Exchange in Clinical Laboratories. The goal here is to provide policymakers with a comprehensive understanding of electronic lab information exchange capacity and activity across the nation. The survey will include information on lab exchange, particularly volume of test results sent electronically, adoption of standards, current information systems used and barriers and facilitators for exchange.

We're planning to use the survey findings to monitor progress regarding electronic lab exchange and to inform policies that promote exchange of structured tests results among labs and ordering providers. We are partnered with NORC to administer the survey through May to a random sample of approximately 12,000 hospitals and independent laboratories and we hope to have results of the survey published this summer. They will be on [healthit.gov](http://healthit.gov), so stay tuned.

Next, I mentioned this before so I just wanted to let folks know that our achieving eHealth equity report has gone up, this was in follow-up to the meeting at the White House back in February, the summit on achieving eHealth equity and a follow-up webinar that took place.

The discussions and the report identified that technology is a powerful tool to reduce disparities among the underserved, but that there are still many barriers that remain, particularly calling out improving the access to culturally appropriate and/or universally designed tools, increasing awareness among minorities about e-Health, demonstrating and publicizing potential of eHealth to address health equity issues and increasing the venues that demonstrate the effectiveness of eHealth tools ability to create health improving instruments for targeted and at risk communities.

This summit is not the beginning of the discussion or the end of discussion, but rather an opportunity to bring together some key stakeholders and to put out some initial thoughts and findings in this report. Again, it is available on [health it.gov](http://healthit.gov).

And last, but not least, I just wanted to let folks know that in April ONC released a snapshot of each of the 17 Beacon communities. It sums up each of the Beacon activities, their demographic makeup, the state of the health marketplace in which it operates and its organizational characteristics. Again, this is – for folks who are looking at what some of the Beacon communities have done, what some of the learnings were and how they accomplished some of their goals. I encourage folks to go again to [healthit.gov](http://healthit.gov), I sound like a commercial, to look at these reports and get a flavor for some of the exciting work that was going on in the 17 communities around the nation. And that's all I have. Thank you.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Very good, Thanks, Jodi. Any questions for Jodi? Okay, thank you very much. This last few minutes wanted to give members an opportunity to raise topics for future meetings. So, in this meeting, we had some Workgroup reports and demonstrated how valuable it is to get input from this full committee to feedback into the Workgroups and for further deliberation some very meaty topics, discussion was very healthy.

We've had updates on activities in ONC at the request from members here and we have ongoing updates from ONC and some of the many projects that are being funded there or are being supervised. What other topics are you interested in having brought to the committee for discussion, for information, for further work? Judy?

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

First of all I thought it was an interesting meeting today.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thank you.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

And secondly, I got a chance to talk a little bit to Maureen over lunch and we talked a little bit about data segmentation. One thing that she mentioned that I thought was interesting was the possibility of an outside engine where you send your data to it, it figures out what should and shouldn't be sent on and then it goes on, I would love that except that I think it might be slow so we would have to figure out could it be fast enough.

The second thing was that concerns me on that is if, in fact, we have to figure out – so you're a university of something or other and you've got a mental health clinic within, a mental health area, I don't know what you would call it that would say, Deven you might know, that would say it's separate enough to be considered separate but it's still under the – yeah, the branch.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Hospital service area maybe.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Yeah, okay, hospital service area, that for us to know what should and shouldn't be shared, I have often asked people can you give me a list of the medications, can you give me a list of test results, etcetera and they say "no." Well, if it's an integrated system and especially if some of the physicians have joint roles and might be practicing with two hats on, and especially if a patient goes to one of those physicians and says "oh, I have a new allergy" what do we share and what do we not share?

And so the safest way to do it would be to actually have those areas, mental health, behavior health, reproductive health, etcetera, on separate systems not to have an integrated system that is the only real clear way that we can say it is separate without risking that the data isn't there.

But there is something else I've often thought maybe we should be discussing which is instead of data segmentation, which one of our fears is that the patients, and Gayle has often said we never want the patient to be surprised, may still be surprised at what comes through, because they might have thought that by hiding certain pieces of information you're hiding everything, but the doctor is a good inference engine and they can still perhaps figured it out. Certainly others, the billing people, the insurance folks, others have access to it.

Maybe instead we should just let the patient create his or her own CCD form, edit the one that is there, create a new one until that patient decides to do it again that new one stays and that way the patient does not have any surprises. The patient knows what's being shared and is totally in control of it and it's a lot easier to do and it's the safest thing to do.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, so the topic then is further discussion of privacy and ways to detect –

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

– a whole different – we've kind of gone down the data segmentation approach as if it is the only approach, but there are other approaches too and that's what I'm bringing up. Should we be going down this – just like HIEs was the first approach but then it turned out that there's multiple approaches. Should we have alternatives?

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, Chris?

**Christopher Boone, FACHE, CPHIMS, PMP – American Heart Association – Director of Outpatient Quality and Health IT**

Yes, I think I have basically; I was just looking at my notes, three topics or areas to consider. The first is going to be around quality and it seems as though Farzad basically opened up today talking about clinical workflow and the integration of clinical guidelines as part of that clinical workflow embedded in the EHR systems. I think that's one topic to further explore.

Another thing that I wanted to pick up on was the secondary use of data that we mentioned in our last meeting and we talked about improving outcomes as being the theme of Meaningful Use Stage 3 and then we also had further discussion about the purpose of many of the third-party registries that already exist that are pretty much owned and operated, for the most part, by a lot of professional societies and we mentioned having more collaborative opportunities with those societies. I think we should pick that part up and really explore what that means, but then also think about all the various efforts that are occurring as it relates to registries across the various agencies within HHS. There doesn't seem to be any comprehensive strategy of sorts of how all of this is being coordinated and maybe I just don't know anything about it. So, that's another thing to consider.

And then the last part is around consumer generated data and the use of that both whether it's captured directly in the EHR and for all intensive purposes used for a secondary use. So, three things I guess.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So, the third one you said coordination of what activities?

**Christopher Boone, FACHE, CPHIMS, PMP – American Heart Association – Director of Outpatient Quality and Health IT**

There are various registry activities whether it be through the FDA, whether it be through the things that we're doing here as well as CMS.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

On your point about secondary use, something that we had talked about was the Patient Centered Outcomes Research Institute and inviting Joe Selby the Executive Director.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

I think they're already on the agenda for –

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

That's slated for next month.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Good, so that's a good opportunity to get at those issues.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, Christine?

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

Thanks, so I had two and they could be related. One is called e-Measurements I think kind of building on what Chris said. I feel like we haven't heard from the Quality Measures Workgroup in a while and I'm not sure if they have activities that are, you know, going on, but I think we need to think very strategically about the way that we can advance quality measurement through all of ONCs, you know, various levers.

but it's so foundational to me for deeming, you know, this kind of deeming approach and getting us to a different construct for meaningful use number one, but also for eliminating health disparities and I just continue to be really worried about our strategy for measuring and working on health disparities. So, and not to mention payment, ACOs, dat, dat, dat, dat so there is a quality measurement piece that I think it might be time to pick back up in probably a more strategic way than what I'm explaining, but you get the general purpose.

And then the other is actually health disparities and I just think there are some opportunities that we ought to think about and there was a recent White House summit on health disparities that focused a lot on, more on mobile or eHealth tools for consumers. So I'd like to think about what the counterbalances and the flipside of how we can begin to get some visibility around reducing health disparities.

And then the last thing I'll say, there are two issues that I'm hoping that Consumer Empowerment Workgroup takes on and so maybe we can see on a future agenda and if we don't take them on we should somewhere in the infrastructure and that is, one care plans, because that is quite an interesting conundrum, we need the technical capability but there's just all this policy issue that I think we need to work through as well.

And then the other is, and this I think the Consumer Empowerment Workgroup is going to take on in the most short-term immediate, which is as we are beginning to open view, download information for consumers they're going to have access to multiple data sets that will probably need some reconciling across and probably some correcting. So, there are some issues around how did their existing rights under HIPAA, which we know a lot about, get implemented in the real world.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Good, Art, oh, sorry, Gayle?

**Gayle B. Harrell, MA – Florida State Representative**

Oh, thank you. One of the things I'd like to see us do is kind of back up a little bit and go back and really hear what the community is saying on Meaningful Use Stage 1. Let's hear the successes and the failures. And there's a lot of information out there and we all read it in the media, we read what Congress is saying and, you know, are we getting the bang for our buck and whatever.

So, I think it may be a good time to pause, do a little evaluation of what we've accomplished, where we missed the mark and as we've got Stage 2 out there and, you know, maybe we need to look at are we moving fast enough, not fast enough. Where are we? And let's do a little evaluation, it's kind of a little time to pause and take stock in what the successes are, what we can brag about and maybe what didn't quite meet our expectations.

I also am very interested in analytics and the use of analytics to improve outcomes and really as we look at quality measures, as we look at cost drivers and where that all goes in taking the information we are capturing if our goal is to improve outcomes and what's out there, and really analyzing and this goes back to something that Neil was bringing up earlier in what, you know, again, what we can do to change those outcomes. That was a very interesting discussion that we had, a very rich discussion; on what they're entity is doing that is successful in really driving outcomes.

How do you – what are the tools out there to make that happen? What can be shared? What's proprietary, what's not? I think that whole conversation really would maybe change directions in what we decide to really put into Stage 3 of meaningful use. So, let's look back and let's look forward.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

I think the ACO Workgroup would be the group to come in and report back to the committee on these issues.

**Gayle B. Harrell, MA – Florida State Representative**

Absolutely, yes, in fact that's exactly where I was going with the analytics and how we're changing behavior with payment models changing, how does that all integrate into those improved outcomes.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Art?

**Arthur Davidson, MD, MSPH – Denver Public Health – Director, Public Health Informatics**

Yes, maybe just to add a little bit to what Chris was saying earlier about registries. So, there are a couple of things about registries that I don't quite understand. Exactly how will a specialized registry be approved in Stage 2? What are the methods? How do we certify that a registry actually – there are lots of registries that out there owned by specialties societies, is there something that this committee could do to make participation in those registries easier for a specialist? Something that the EHR could do to make it easier to participate?

There is in this year's Medicare legislation, something that says that the GAO is going to study qualified clinical data registries and I'd like to understand what they're going to do and how that might influence the way that CMS would move forward with specialized registries and how I think having those registries is getting to some of the points that Gayle and Neil were saying earlier is how do you measure and find where there are improvements or better outcomes than in others. So, we have an opportunity to use the registries to support that.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Good. Neil?

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Just a general point, we were fortunate to have Dr. Patrick Conway on the Policy Committee and I think he's really at center of a lot of the implementation of quality reporting in general and then the incorporation of registries. So, I think for one of the future Policy Committee meetings where he's able to attend we can ask him to give us an update on those activities.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

Can I add to that, I think the other thing I was interested in is how we could pursue the possibility of using meaningful use as an innovation pipeline for new measures and whether that's practical or not. I think since we put that out as a question in the RFC I've had some conversations with, you know, members of the public and there are definitely some real questions that have to be answered and challenges around the affordability of creating new measures and therefore who can do it and afford to do it, etcetera. But I think it's actually possible.

And so I'm not sure what work is happening at ONC to really investigate that pathway, but I want to make sure that we keep thinking about how to do that because it could potentially be a really nice pipeline for measures that are not just the existing ones retooled, but are really IT enabled measures in the way we've always intended.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Thanks. Neil?

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

So, I have a couple of thoughts. One I think we had committed last time to get updates from the CommonWell Health Alliance and I think we need to keep that on the radar because of the possible sort of crossover I guess between what's going on there and state exchanges and other exchanges, which I still don't understand how that's all supposed to fit together at some point. So I think we should continue to track that.

And that also the whole issue of sort of what's going on in states and how that either is consistent with or potentially at odds with some of the work that we're thinking of. I remember Farzad's comment that, you know, the national data exchange is going to be lots of things happening in lots of places in lots of different ways that are going to come together through standards and I think that that's great but it would be good to get a sense of what's happening for those of us who live in one state just sort of how is this coming together? Like what's happening across the country? Maybe a little bit of a survey not just about adoption of HIT but also about what's happening in terms of exchanges across the country.

And then I think it would be great thinking about the way the meeting talked today about outcomes. I think it would be great to have some presentations of places that have had sort of breakthrough outcomes in whatever they are, whether they're patient safety things are other stuff based on IT. I think it's really important in the current environment that we share success stories, you know, we're struggling through the weeds but there must be success stories, places that have achieved sort of breakthrough performances in various areas and I think that would be a great thing to share with the group so that we can learn from them not just specifically about that but about the processes that it took to sort of get there.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

Can I make a comment?

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Go ahead.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

A lot of the issues that came up on the discussion about CommonWell were not specific to CommonWell, it was really more about and I guess to your second point about concerns people have about the EHR vendor being in kind of the critical position of providing not only the EHR services but also being in kind of a control point in terms of providing health information exchange services.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

Yeah.

**Farzad Mostashari, MD, ScM – Office of the National Coordinator – National Coordinator**

So, I think if we do have the conversations it probably makes sense to broaden it not just about CommonWell but about EHR vendors, you know, if we're talking about HIE the verb, right, and many different ways of providing that information exchange but when we're talking about EHR vendors and a governance of EHR vendors and the potential, you know, whether it's open to other forms of information exchange if they also control a physician's desktop those are all I think more generic issues that we should potentially take on.

**Neil S. Calman, MD, ABFP, FAAFP – The Institute for Family Health – President & Cofounder**

And two other things I just wanted to mention. One is that we don't really talk a lot about the cost of systems and I think that while that may be seen by some as sort of the downside of, you know, how much providers are spending on IT overall, I think it's really important to track that as kind of people are paying more and more attention, I know in New York State and elsewhere, about trying to limit the administrative costs in the provider community.

And I think it's important to recognize that the kind of processes that we are creating have great benefits but also have costs associated with them and we should try to get a handle on what that is so that we can make sure those costs are covered especially I think in the safety net community where there are specific issues.

And lastly, it is just a plea that today was abbreviation hell, for those of us who don't live in this world, you know, just having all of this stuff sort of thrown out is really – I mean, you kind of just get lost in the conversation and then you kind of blank out and I think it's an educational thing.

We're also broadcasting this to the public and I think that there are a lot of people who may not know what we are talking about and we should just be careful because, you know, whether we're doctors or lawyers or whatever we have to learn to speak in language that everybody understands so everybody can understand what is happening in the meetings.

And I would just – maybe I'll make a point of screaming out in the next meeting every time somebody uses an abbreviation that we don't understand, but some of today just was a nightmare at times and there seem to be new abbreviations that come out – I mean some of them I know that I don't know because I've heard them before but some – I mean there were at least 10 new abbreviations I saw today or things that I had never even seen before.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, I need to try to wrap up if that's okay. So, let me try to summarize, thank you for those rich suggestions. I think some of them can be cubbyholed so let me try to do that. We began with Judy's concern over essentially a lot around privacy of sensitive data. So, one I will say that NCVHS wrote a letter about this and so I think it will come up in this scenario three some of it. I mean, some of the concern was around how do you inadvertently or on purpose discover sensitive data when you're doing a

–

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

– alternative –

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Correct.

**Judy Faulkner, MS – EPIC Systems Corporation – Founder & Chief Executive Officer**

Data segmentation that give the similar result.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So it's still that issue and I don't know whether – so some of it can come up in this scenario three re-deliberation some of it can come up in other areas planned is that true?

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yes, absolutely.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

Yeah, I mean for example one of the things we've had in our long-term plan is the issue of minors.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yeah.

**Deven McGraw, JD, MPH – Center for Democracy & Technology – Director**

So it comes up there too.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yeah it's how to deal with "sensitive data" and there's lots of different kinds. Chris talked about quality, a number of topics, quality improvement, registries, secondary use tied to registries and patient generated data. I think there's actually a Workgroup on data intermediaries, correct? Am I in the right?

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

There is a Tiger Team under the Quality Measures Workgroup.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Okay, so that actually is going to be taken up deliberately and then it will weave its way through in sort of the deeming process in meaningful use. So, it is on the agenda, in fact there is a whole Tiger Team on that.

With regard to patient generated data that presumably will be under the Consumer Empowerment Tiger Team or Workgroup?

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Workgroup.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Workgroup I guess and also your talk about care plans, you put on your agenda.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

Yeah it wasn't patient generated it was data.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Correct.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

– specific.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

But, so two topics though. I mean, you talked about patient generated data as well.

**Christine Bechtel, MA – National Partnership for Women & Families – Vice President**

You want to put that on there because you're on –

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yeah, does that make sense? Gayle talked about hearing about what are the successes and the lessons learned in the entire sort of EHR incentive program, meaningful use taking a forefront, there may be a way to get an update. We get snapshots, we got snapshots from – we get it from CMS every month, we get some from the ONC, I don't know that we've seen it all together, it's pretty impressive, but what might – what we might do is someone present almost the quick steps because there is a visual representation but I don't think we've seen exactly what the impact of the program has been.

**Gayle B. Harrell, MA – Florida State Representative**

And more than just numbers.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Yes.

**Gayle B. Harrell, MA – Florida State Representative**

You know, success stories.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Correct.

**Gayle B. Harrell, MA – Florida State Representative**

You know, I think we have a product to sell here and I think there is an audience out there that doesn't understand what our successes have been and what is really going on.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

So that was my second point which is I think Beacon is a way to do that for more than one topic is Beacon was designed to take some of the advanced uses and say if the world were more like that what could we achieve. And they're just winding down. There is the March report. So, we might be able to put together – I think some of this is packaging it's like putting in one place and telling the story like you say Gayle.

**Gayle B. Harrell, MA – Florida State Representative**

And you have to tell it simply and succinctly without the acronyms.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Right without the acronyms, so in human speak. The other potentials was one the new Workgroups on ACO so their value proposition has a different perspective it says how do we manage an entire population, how do we be accountable and what are the tools that are needed and is what we have now good enough or what needs to be done? So, that's another perspective I think we can roll into the ACO Workgroup.

I think Art talked more about registries, Farzad talked about how – and there were a couple of mentions of quality measures and Christine mentioned as well, what's the quality measure strategy of the future that's something presumably – Patrick Conway, I mean that what he worries about and what is CMS doing, what are the things coming down the pipeline. As Christine mentioned we haven't really had an update from the Quality Measures Workgroup, it's under new leadership, you know, Helen Burstin and who else is Co-Chairing that?

**W**

Terry Cullen.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Terry Cullen, sorry, are Co-Chairing that and so their new strategy which has shifted would be important to get an update on so that would be a good way of dealing with that. Farzad mentioned – addressed what Neil raised in terms of CommonWell what Neil raised but it's really more generically, what are the alternatives in exchanging information, states, the acronyms is self-explanatory.

So, there's a number of things I've put on the table, fortunately most of them are covered by groups that have an active agenda, but it's useful to have all the leaders here from you all about what is on your mind. Okay. So, why don't we move to public comment please?

**Public Comment**

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Operator, can you please open the lines for public comment? And if there is anyone in the room that would like to provide a public comment if you could please come to the table.

**Alan Merritt – Altarum Institute**

And if you would like to make a public comment and you're listening via your computer speakers please dial 1-877-705-6006 and press \*1 or if you're listening via your telephone you may press \*1 at this time to be entered into the queue.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

There is no public comment in the room. Any public comment on the phone?

**Alan Merritt – Altarum Institute**

We have no comments at this time.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead**

Okay.

**Paul Tang, MD, MS – Palo Alto Medical Foundation – Vice President, Chief Innovation & Technology Officer**

Well, thank you very much and I think I agree with Judy Faulkner that this was a good meeting and productive healthy discussion. I am trying to apply the airline rules which is if you land within 15 minutes of your scheduled time you're considered on time. So, we're only 10 minutes, so I'll just keep trying to get better and stay to the minute, but at any rate, thank you everyone for coming, for participating and we look forward to talking to you next month.

**Public Comment Received During the Meeting**

1. For the public health measures, are statistics available for the % who successfully performed a test vs. an unsuccessful test (which counts for Stage 1)?
2. Technology is NOT in early stages – being used for over 10 years for addiction and mental health treatment
3. The fact that many states have been using one source segmentation technology for years has been ignored by this committee, despite the Consumer Choices Technology Hearing in 2010.
4. Further, all EHRs must be able to "segment" erroneous information to protect patient safety. The functional capacity for segmentation is the same as needed to segment sensitive information.
5. This entire discussion does not even contemplate data exchange via patient control ---the committee is totally out of step with what the public expects and has rights to. The public will not support continued control over use of PHI by institutions and data holders.
6. Open queries by strangers that patient have no knowledge of is a bad plan. We need a "chain of custody" for all downstream uses of PHI, until we can transition to patient-controlled data exchange. I would be glad to present a 5 year plan for transitioning from institutional control over PHI to patient control
7. The RLS could be a list of patient emails (chosen by themselves or assigned)----patients can control how they they are reached. They understand how to connect to banks and websites via their own chosen email address. Patients can connect and send PHI from one physician to another---that is the simplest way to move data with clear consent.
8. Today Harvard Partners does not allow segmentation via "Provider type" in its plan.
9. Harvard Partners prevents patients from being able to segment data as required by MA law. Partners seems to think it can set policies that violate patients' rights to make granular or even gross visit-based choices.
10. Patients should be able to limit queries----that is who has rights to make those choices.
11. Patients should be able to refuse the choice of aggregator services. Patients have no way to even know who all these hidden collectors and users of their data are.
12. The way to look for patients' records is to ask the patients.

13. YES record locator services are TOTALLY hidden from patients
14. Why would you assume patients do not know who their doctors are?
15. HIPAA does NOT control records disclosures---stronger state laws and federal laws and medical ethics prevail.
16. Building systems that do not comply with stronger legal and ethical rights will cause patients to avoid treatment and not trust health IT.
17. The policy guardrails are all set by industry and government---"sharing is caring" is WRONG---patients ONLY want or agree with sharing when THEY decide for themselves. who sees what.
18. All of these silent, hidden users and holders of data are not trusted.
19. Tiger Team discussion is too generic to understand how this is supposed to work. Assumption that Scenario 3 then turns in to Scenario 1 or 2 means nothing without examples and analysis as to whether the combination of these scenarios actually covers all the real word possibilities.