



**HIT Policy Committee
Privacy & Security Workgroup
Final Transcript
November 10, 2014**

Presentation

Operator

All lines bridged with the public.

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

Thank you. Good afternoon everyone this is Michelle Consolazio with the Office of the National Coordinator. This is a meeting of the Health IT Policy Committee's Privacy and Security Workgroup. This is a public call and there will be time for public comment at the end of the call. As a reminder, please state your name before speaking as this meeting is being transcribed and recorded. I'll now take roll. Deven McGraw?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Here.

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

Hi, Deven. Stan Crosley?

Stanley Crosley, JD – Director, Indiana University Center for Law, Ethics & Applied Research (CLEAR) in Health Information - Drinker Biddle & Reath, LLP

Yes, here.

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

Hi, Stan.

Stanley Crosley, JD – Director, Indiana University Center for Law, Ethics & Applied Research (CLEAR) in Health Information – Drinker Biddle & Reath, LLP

Hello.

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

Adrienne Ficchi? Bakul Patel? Cora Tung Han? David Kotz?

David F. Kotz, PhD – Associate Dean of the Faculty for the Sciences – Dartmouth College

I'm here.

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

Hi, David. David McCallie?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

I'm here.

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

Hi, David. Deb Bass? Donna Cryer?

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

Here.

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

Hi, Donna.

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

Hi.

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

Gayle Harrell?

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

Here.

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

Hi, Gayle. Gil Kuperman?

Gilad J. Kuperman, MD, PhD, FACMI – Director Interoperability Informatics – New York Presbyterian Hospital

Present.

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

Hi, Gil. Gwynne Jenkins? John Wilbanks? Kitt Winter?

Kitt Winter, MBA – Director, Health IT Program Office – Social Security Administration

I'm here.

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

Hi, Kitt. Kristen Anderson?

Kristen Anderson – Staff Attorney, Division of Privacy & Identity Protection – Federal Trade Commission

I'm here.

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

Hi, Kristen. Linda Kloss?

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Here.

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

Linda Sanches?

Linda Sanches, MPH – Senior Advisor for Health Information Privacy – Office of Civil Rights

Here.

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

Hi, Linda.

Linda Sanches, MPH – Senior Advisor for Health Information Privacy – Office of Civil Rights

Hi.

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

Manuj Lal? Mark Sugrue? Micky Tripathi? Sephania Griffin? Taha Kass-Hout? And from ONC do we have Kathryn Marchesini?

Kathryn Marchesini, JD – Acting Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Here.

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

Hi, Kathryn and Helen Canton-Peters?

Helen Canton-Peters, MSN, RN – Office of Chief Privacy Officer – Office of the National Coordinator for Health Information Technology

Here.

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

Hi, Helen. With that I'll turn it back to you Deven.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay, great, did anyone...is anyone on who missed the...who missed getting their...who missed roll call or didn't hear their name? I thought I heard a voice, an additional voice. Okay. I'm hearing things this is good news. Okay, thank you all for joining us today. We are going to talk...we're going to spend the bulk of our call today trying to plan a hearing or we could call it a listening session if we want to on this issue of health big data.

When Stan and I, and the team from ONC, and our support team from MITRE coalesced after our last call we thought that one of the ways that we could sort of both scope out the issues but also give ourselves kind of a firm foundation for drawing some parameters around how we want to attack this issue that we, you know, could really start with some information gathering and it's something, you know, for those of you who are new to this working group we've had a number of sort of hearings or listening sessions over the years some of them have been in person but more recently we've been having them virtually on-line open to the public and they've worked really well.

They have been some of our very best sessions in terms of, you know, our capacity to gather information and to really suss out a number of issues that come out either during the presentations by people that we ask to give specific presentations or frankly, more likely, in the Q&A that occurs after the presentations with members of a panel.

And so we really felt as though, you know, given that we're sort of very, in the very early stages of trying to tackle what is an enormous set of issues around health big data that in order to respond to the charge from both HHS and the White House that we might start with moving ahead and getting some foundational information that comes through...I'm calling it testimony it's not like congressional testimony it's not that official, but through these listening sessions.

And so what we're going to do today is to talk about some topical areas that Stan and I and the staff have identified as being sort of potential panels that would take place during these listening sessions and then begin to get some suggestions or get your reaction on those panels maybe they're not the right ones, maybe we need more, maybe we need less. I want to get all of your feedback on that and then begin to suss out potential panelists.

We are going to try to, you'll see this on a subsequent slide, but I'll go ahead and spoil the ending, we are looking at some fairly fast timeframes for this some open dates in December, December 5th and December 8th in part because there are not very many dates available to us in December when we can do this. Later dates in December that are available are much too close to the holidays and we would risk losing not only our membership being able to be on the phone but also being able to get a good set of panels of people to present information to us.

And then if we wait until January we're likely to have to do more of an interruption, you know, we are going to get the interoperability roadmap that's going to be publicized and that we will need to turn to that in order to generate some feedback for ONC on that roadmap and if we don't manage to squeeze in these listening sessions or hearings in December we may end up putting off our big data discussions for much longer into February or March and so to really get started on this topic and make timely progress on it we were going to try to pull this off in early December which does mean we need to really get robust suggestions from all of you both on the topics as well as the potential participants.

So, before we launch into the topics Stan is there anything I left out?

Stanley Crosley, JD – Director, Indiana University Center for Law, Ethics & Applied Research (CLEAR) in Health Information – Drinker Biddle & Reath, LLP

No, thank you, you did a great summary and good.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay. Any questions about the idea of beginning our work on this issue with listening sessions or hearings, again, we can decide what we want to label it? The outcome is the same. Okay, let's move to the next slide, please.

These are the five buckets that Stan and I, and the staff have identified as potential panels for the two days and it wouldn't be two full days by the way in case anybody is panicking. At the moment we're looking at two afternoons.

They are health big data opportunities, the learning health system, health big data concerns/harms, protections for consumers and then what does current law provide on any of the foregoing topics. And so that's the big picture look at the different topic areas for which we are proposing that we do panels. And let me spend the next few slides telling you what's in each of those buckets.

First slide, next slide, thank you. So, here for the first panel this is really a bit of an environmental scan to get some snapshots of what's happening out there.

W

Hey, Deven, I'm sorry, what slide are you on now?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

I'm on slide four.

W

Thank you.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

You're welcome. And this is about trying to, you know, just get a snapshot of what's happening out there today and so ideally not, you know, sort of speculation about what could happen in the future although certainly there is room to do that but I think we want to start with sort of at least understanding the landscape of what's either happening now or in immediate plans with respect to collections and uses of health big data.

And here are some potential subtopics, you know, clinical data combined with consumer provided data to improve individual and population health, genomic data, innovative uses of device data, the PCORI funded initiatives, PCORI being the Patient Centered Outcomes Research Initiatives for those of you who aren't familiar with the acronym, transparency and performance measurement, mobile Apps and social networking site data and use of essentially what's non-health data but can be used for health purposes to make inferences like predictive models for example on medication adherence just to provide one example where you could use non-health data to be reasonably accurate in predicting who is likely to be compliant with a medication regimen. Next slide, please, slide five.

Then we've identified another topic which is the learning health system and there is arguably a bit of an overlap between these two buckets, buckets one and two, but I think what we're talking about here is trying to be much more focused on the types of big data uses that are critical to the learning health system and the different types of analytics that are involved there.

And here there are actually buckets on this slide and two sort of broadly defined types of data, big data, that are important for the learning health system, one being, you know, analytics data that is information in an anonymized or even aggregated state which might be a better way to refer to it.

And then in the other bucket which we've sort of preliminarily defined it as precision medicine where it's important, you know, to sort of know who the particular patient is and be able to have records track that patient longitudinally over multiple health systems and through multiple encounters, and what are the sort of learning health system goals that can be met with one type of data versus the other and are there, you know, distinctions in terms of both the opportunities and the concerns that we need to think about.

And then the next topic, next slide, please, slide six. So, then in the next sort of broadly scoped panel we want to get some sense of what some of the concerns and harms are. So, slide one and slide two are a lot about opportunities, although I think the learning health system slide can certainly begin to start to get into the concerns or issues, or harms but we really do want panel number three to sort of focus on what makes people nervous about this, what do we have to worry about and to provide some real examples, if we can, but certainly, you know, hearing from civil rights groups, consumer groups, privacy advocates and others about what they're concerned about with respect to health big data use. Next slide, please.

And then on slide seven we've identified sort of two more topic areas for which we would have one or more panels, one being what is the universe of protections that we might want to deploy in order to meet the harms or concerns that are surfaced in the prior panel and this is both about, you know, sort of...it's not so much about current law although I think current law would obviously have to come into play here, but sort of understanding the protective value and limitations of the various tools that we do utilize to try to protect patients in health big data circumstances.

And then we do want in the last panel, at least again as we've proposed it here for discussion today, is to talk about, you know, well what does current law get us in terms of the protections and where are the gaps and, you know, ideally we would tap into our friends from within the various divisions of HHS and also the Federal Trade Commission and other relevant oversight bodies to try to get a sense of what the tools in the arsenal are and what more might need to be done to maximize the opportunities that we've uncovered but to minimize the risks and the concerns that we surface in the earlier panels.

And so with that, let's see what's on the next slide, okay. So, with that I want to...Stan I'm going to turn to you to see if there's anything that I left out in terms of discussing the topics and then we'll open it up to others to get some feedback on how we've sort of scoped this out, is it right, is it wrong, is it close, way off? So, Stan anything you want to add before we open that up?

Stanley Crosley, JD – Director, Indiana University Center for Law, Ethics & Applied Research (CLEAR) in Health Information – Drinker Biddle & Reath, LLP

Yeah, I think you did it pretty well Deven, in that really the buckets are somewhat intentionally vague when you get into things like, you know, in the learning health system...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah.

Stanley Crosley, JD – Director, Indiana University Center for Law, Ethics & Applied Research (CLEAR) in Health Information – Drinker Biddle & Reath, LLP

Anonymize versus identifiable, we didn't really go into, you know, HIPAA de-identified versus identifiable, you know, we're just talking about the buckets that we want to talk through and hopefully the issues will come out as we have these learning sessions. So, I think it was kind of the idea, at least anyway, to start somewhat vaguely at least for this conversation. So, I think it's...I think we're in good shape.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

...

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

This is Donna, one of the questions I had was, do we think that there is a, just a level set to the common definition and understanding of what big data is so that when we have these conversations and panels that we are sort of talking about the same things.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

You it's a good question Donna. So, on our previous call we sort of assumed that we would at least loosely sort of take into account the definition that's in the White House Report, which is, you know, the three V's, volume, velocity and variety, but not necessarily be confined by them. In other words, you know, if someone thinks that health big data means, you know, the ability to amass records across multiple institutions in order to do research but is not...it still would be big data even if it doesn't reach some sort of magic number in terms of volume that I think we still want to consider it.

You know for those of you who have read the White House Report there are a couple of provisions in there where they talk about how, you know, the regulations might work very well for small data but don't work as well for big data. Well, you know, given the sort of looseness and definitions around big data it's a distinction that isn't, at least in my view, all that helpful.

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

Right. Well and I didn't know...and forgive me for missing the last call.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

No that's okay.

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

But is part of our purview to sort of, you know, encourage the adoption of this sort of definition and thinking as things move forward for more consistency or is it still very much a matter of, you know, getting the feedback to make sure that we have the right, you know, definition so that the right policy and regulations can flow from what, you know, people in the field commonly agree is, you know, the big data discussion.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

You know, so, I think, my assumption and it's certainly up for debate, is that we would be better off at this sort of foundational hearing phase at not landing on a specific definition...

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

Okay.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

And drawing firmer boundaries so that we can get the maximum amount of feedback and then we might ultimately decide that in fact there is this distinction between small and big data and here's where we think it is and we're going to focus on, you know, one versus the other.

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

Okay, excellent, thank you.

Stanley Crosley, JD – Director, Indiana University Center for Law, Ethics & Applied Research (CLEAR) in Health Information – Drinker Biddle & Reath, LLP

I agree with that too because I think the other thing is that we run the risk if we do define it that we eliminate a lot of the things at the very beginning instead of through the process. So, maybe at the end we'll have a better idea.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, this is David McCallie, I agree with that cast a broad net and then we'll look back in retrospect and maybe narrow it, but it's such an open definition, so many different meanings we don't want to try to subset it too quickly.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Hi, this is Linda and I certainly, Linda Kloss, and I certainly agree. I think it might be helpful in framing the invitation to any who are going to participate in the listening sessions that this has been...that we've deliberately done that.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, that's a good point.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Good point.

Stanley Crosley, JD – Director, Indiana University Center for Law, Ethics & Applied Research (CLEAR) in Health Information – Drinker Biddle & Reath, LLP

Yes, right again.

Mark Sugrue, RN-BC, FHIMSS, CPHIMS – Chief Nursing Informatics Officer – Lahey Hospital & Medical Center

This is Mark Sugrue, in sort of the same vein in terms of messaging I'd argue with number three the concerns and harms maybe recasting that a bit to talk about big data unintended consequences or something along those lines just to soften it a bit. I get the point but it just seemed a little alarming the way it was laid out.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay, are we sure they're always unintended?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, I'm not sure, I think that's a good phrase to add to the slide.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah or we would hope...so the term "harm" is actually one, well let's think about how...I'm trying to think about how the White House Report plays that, you know, they urge ultimately more of a, you know, focus on uses and, you know, the point is well taken, right, we don't want to mislabel necessarily what the issues are and presuppose a set of answers that they're harmful or concerns and I wonder if we go back and look at that report if there is sort of a better way of framing that to get at what we're trying to surface which is really a range of issues that people have raised that may need to be dealt with in order to, you know, build a trusted environment and a proper regulatory framework for big data, health big data.

Kristen Anderson – Staff Attorney, Division of Privacy & Identity Protection – Federal Trade Commission

This is Kristen Anderson, I don't know if this helps at all, but we sometimes talk about unanticipated uses which could fall under the umbrella of concerns or harms. I don't know if that helps soften it at all.

Mark Sugrue, RN-BC, FHIMSS, CPHIMS – Chief Nursing Informatics Officer – Lahey Hospital & Medical Center

Yes, it does.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Thanks, Kristen.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

This is David, I mean, I think there could be an unintended use or a intended use that could have an unexpected side-effect that wasn't part of...in other words it might not be a use per se but it could hurt or harm as a side-effect. So, it doesn't have to be a use to be harmful.

I assume that use means something that you planned and that you said "I'm going to take the data and do this with it" there could be side-effects of that which are unintended and could cause harm. There could be unintended benefits too, but that's hopefully not a problem that we're too worried about.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

We...I think one of the concepts is certainly the concept of repurposing and reuse that we should talk about as a risk because I think it will frame some of our recommendations going forward.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, I'm thinking of things like, you know, if you use population data in the broader sense of population like in community to highlight opportunities for improvement of public health and community resources you could have an unintended consequence that makes it easier to red line and avoid that community, and, you know, no one would say that's a use of the data to try to keep people away from the community but it might be a side-effect of exposing the data to try to highlight what the deficiencies in a community are for example.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Might it be helpful to go back to slide four and just walk through what you've got bulleted under each and see if we can offer any additional suggestions?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Sure.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

I would...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

We could go through each of the slides actually that's a really good suggestion Linda.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

On slide one...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

I would...

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

The opportunities, I had thought that what seems to be missing there is the perspective of public health.

M

Right.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Deven, this is David, I was going to say that, I'm sitting at this Robert Wood Johnson Foundation Forum on data for health and one of the things that's come out to me is when people say population health there are really two completely different definitions of it.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Those of us who come from the care delivery side think of it as a defined population for which you take responsibility and risk of managing their health and their care but the public health crowd takes population health to mean community health, the health of a community not with respect to care delivery assignments and contracts, but actually how healthy is the culture in the community. So, maybe you add a category called “community health” or “public and community health.”

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Yes.

Mark Sugrue, RN-BC, FHIMSS, CPHIMS – Chief Nursing Informatics Officer – Lahey Hospital & Medical Center

Good suggestion.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

To that point, this is Linda Kloss, the NCVHS last Friday, I guess it was, we approved a work product called a toolkit for community...for the use of data by communities who are using health data for improving care in the community and I think that might be a resource that I'll circulate to the Workgroup, but we began by framing not laws and recurrent regulations but fair information practices. So, we might look at how that application maybe useful for this discussion.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Interesting.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, this is David, I just heard about that toolkit from Larry whose last name I'm going to blank on, who is here...

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Larry Green.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Larry Green, and he makes an eloquent defense and explanation of what they're doing and he is somebody to put on your list of possible candidates for your panels. He is very articulate.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay, who is Larry?

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Larry is chairing the NCVHS this year and is the Director of the Family Practice Community Health Program at University of Colorado. But, Leslie Francis could also present the toolkit.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay, good suggestion.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

But lots of good examples I think in that which are very relevant.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes, yes. You know so one of the challenges for us will be not only to sort of identify what's potentially missing on this list but also to, you know, be able to plan a panel that is manageable within the...I mean, we'll do some time allotments it could be that, you know, not all these panels necessarily need to be the same size and it might be that we cast a large net for this one.

But, while we're on here since we were starting to get into some suggestions of panelists I want to continue to get feedback both...really on both things, one what other types of health big data do people not see on this list that they think we need to include in a sort of scoping opportunities panel and who we might have. And if there is anybody that covers more than one of these categories even better.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

This is David, I just noticed you do have social networking data.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

I wouldn't maybe put it underneath mobile App.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Because that might be a bad...I mean, maybe those are separate categories but I'm thinking for example there is a lot of news the last week or two about the Twitter App that supposedly can detect suicidal thoughts based on Twitter feed and the controversy that sprung up around that, that's the kind of thing that would be, you know, a big data use that may or may not meet everybody's definition of a good thing.

David F. Kotz, PhD – Associate Dean of the Faculty for the Sciences – Dartmouth College

Yeah, this is the other David and I was going to make the same point. Mobile and social are distinct.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay.

M

We're heading down the wrong way, Deven, on narrowing.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

I know.

M

These are great points though, they're great points.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Deven, where do you have the data broker companies slotted anywhere in these slides as a category?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

So, we did not divide these by actors.

M

Right.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Right.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

So, what we're looking for...so where would...if we want to hear from a data broker would we ask them about how they're maximizing data to contribute to opportunities or would we highlight them for example in the next slide around learning health systems.

M

They can play in either the last two buckets on topic one.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Right.

M

And they could certainly play in this bucket a little bit.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, it just seems like a lot of the population health companies are beginning to integrate some of that traditional marketing data broker data.

M

No question.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

You know lots of opportunities, but not necessarily all good.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

And this is Linda Kloss and I think perhaps another addition to number one is some of the public use databases.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Like?

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Well, like all of the data that hhs.gov and some of the states and others.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Census.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Datasets that are now just so many of them.

W

Like the CMS datasets and then...

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Yeah.

W

And the open FDA project...

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Yes.

W

And things like that.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Yes.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes. Is there any one person in HHS that could give us a brief overview of a bunch of those as opposed to asking separate people to...

W

I wonder if like Ryan...or something could do that or Claudia Williams.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, we can talk off line but it seems to me that again if we have...let's go back to the previous slide four, please. If we have, you know, any particular person that hits more than one of these it's helpful.

You know the other thing we will do is, you know, we'll build the best panel we can for this and also ask MITRE to help us gather information off line to supplement our knowledge with what we can't get in testimony because I think it's just going to be impossible to, you know, sort of grab...to get everything covered through panelists. We may need to prioritize a bit here.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

And you may want to split panel one into two separate sessions, you know, part one and part B or something.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, well, if it doesn't get too big we will inevitably have to do that.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

This is Linda Kloss and maybe the way to frame number one will be to get down to the level of what questions we want them to address because each one of these could be a panel.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Right.

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

But we're really focusing on the, you know, stewardship dimensions, the privacy and security issues are we not or are we looking broadly at all the ways that data are being used?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

I...

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

I just am not certain that the latter is going to be terribly productive.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Well, I think the idea is, you know, on our last...I'll share with you why we planned it this way but we can certainly, you know, certainly taking feedback from all of you because part of the purpose of doing this listening session is to help us prioritize and place parameters around, you know, to get a plan of attack for this issue, we can't take on the universe as big as it is. But we actually, Linda, did think of this as the latter...

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Okay.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Which is the say, let's understand why people are excited about this and why this has become, you know, for...whether you believe it or not the buzz word or the hype of the year in terms of sort of the...people are pinning their hopes on this in many respects.

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

Deven?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

And is that warranted, not warranted, what's really going...you know, just to get a sense of what's going on out there as opposed to beginning already by surfacing the protections issue...

M

Right.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

And have that issue be covered in later panels. That's what...

Linda Kloss, RHIA, CAE, FAHIMA - President at Kloss Strategic Advisors, Ltd.

Thank you, Deven, I did miss the last call and apologize.

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

Deven...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

No, that's okay a lot of people did.

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

I was wondering if...this is Donna, I was wondering if this could be, since there are, you know, so many different parts of it, my vision of this might be a, you know, a single speaker doing sort of a general, you know, landscape, you know, this is where we are, this is the opportunity but then to the, you know, prior speaker...and then these are the questions, you know, it raises.

So, I think that might be, you know, more efficient in terms of, you know, time and then, you know, better able to, you know, there are a of ornaments on this Christmas tree here, but to sort of have somebody who can sort of wrap it all into sort of one unifying theme and set the stage for the panels to further, you know, the big bucket aspect of it.

Linda Sanches, MPH – Senior Advisor for Health Information Privacy – Office of Civil Rights

Deven, this is Linda Sanches, I'm wondering if someone from AHRQ or ASPE might have some ideas because they are both big users of these kinds of massive data sets.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

That's good, yes.

Gilad J. Kuperman, MD, PhD, FACMI – Director Interoperability Informatics – New York Presbyterian Hospital

This is Gil Kuperman, you know, just...and maybe it falls into the category of, you know, what are the questions that are going to be asked, but, you know, the folks who are kind of grappling with this every day, you know, what are the hurdles that they see to progress, because, I mean, I guess the way I think of it is that this is, you know, potentially a powerful technology, the privacy and security aspects are, you know, complicated and, you know, the folks who are really trying to do this every day are they running into those, you know, and if so how and, you know, what, how would their progress be accelerated, you know, what kind of clarity could help them accelerate progress. I mean, I don't know if that's exactly one of the goals that we want to have but, you know, I'd be eager to know, you know, what pain is being felt out in the real world.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

So I want...I'm realizing Gil as you're talking, I'm looking through my paper copy of the slides and I'm like, You know, I don't think we have, you know, sort of obstacles to maximizing big data opportunities...

Gilad J. Kuperman, MD, PhD, FACMI – Director Interoperability Informatics – New York Presbyterian Hospital

Yeah.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

We don't necessarily have that.

M

Right. Well, I mean, have it...we actually it kind of scattered throughout a little bit, I mean, you know, you could say in some areas there is regulatory or legal barriers and in some areas there is, you know, identification and re-identification barriers so I think there are some barriers scattered throughout but it's probably worth, as you talk about the opportunities, talk about the barriers to realizing the opportunities.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, does that...so I'm...in this next, so on slide five, the topic that's, you know, the learning health system.

M

Yeah.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Do we...is that a good place to sort of get some folks to talk about the pain points and the...

M

Yeah, I think so. I like that idea.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Yeah, this is Linda, and I was toying with the idea of rolling maybe the learning health system into opportunities because it is one of the opportunities and then maybe breaking one into Part A, Part B but asking that question that Gil raises to anyone testifying...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Right.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yes, that makes a lot of sense.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

...the opportunities and obstacles.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

That makes good sense.

M

Deven, you know, I think it's worthwhile to kind of come back and think about this a little bit of how much time we're going to have and what we're reasonably going to be able to accomplish during these listening sessions and obviously we're not going to get to any resolution, hopefully we'll be able to kind of highlight some of the big issues that pop out, right?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah.

M

I mean, so I think, you know, we can fine tune this a lot but ultimately I think it's going to be, you know, big data is going to be a little bit messy as we try and hone in on issues but hopefully after two days or two afternoons we'll at least have an idea of what we now need to focus on more. Is that consistent with what you think?

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

This is Gayle, I would just like to add that I think questioning and leaving enough time for open questions really brings out so much more than...you know, especially when you want to talk about obstacles and things of that sort that ought to be part of the whole framework we're thinking of and questioning as we move forward in each of the panels.

M

So, you mean, just a question and answer session for each panel?

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

Yes, I think we need them that is absolutely essential that there would be a question and answer period for each panel.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, it is generally where some of the best information has come out in our previous hearings or listening sessions has been in the Q&A where there is really an opportunity to drill down so we can't overload the panels to the point where we preclude that discussion.

M

Right.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

You know inevitably we won't be able to hear from, you know, even all of the people we might like to and we'll have to make some choices to try to get the best...

W

I think even...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Representation of what we're...

W

Even in terms of the panel, you know, format and forgive me for breaking in because I'm muting myself most of the time.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

That's okay.

W

So, I'm playing like double-dutch and I apologize if I skipped on a point of yours, but I was thinking even as we, you know, think about how the panels themselves operate if, you know, sort of a three step process of them, you know, sort of presenting from their perspective or experience so then, you know, having sort of a moderated discussion amongst the panelists because, you know, we're going to invite some really great people who are doing exciting work and often may not get a chance to sort of talk amongst themselves and ask each other questions and that then will help spark and create really a discussion setting environment with the audience so it's not just, you know, a question, you know, a presentation and a question to the panel but really we're thinking about, you know, everybody there having one big discussion that starts with the panelists among themselves.

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

Deven, this is Michelle, maybe it would be helpful if we provide for the new members what we have done in the past to kind of execute the hearings. If you want me to talk to that at all?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Do you mean from a logistical stand-point or just a format?

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

Well, yeah, logistic and format.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, sure.

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

So, for most of the listening sessions, which we've done a lot of them now, so I think we've figured out the process fairly well, we usually limit the comments from the people that we ask to testify to five minutes. We send them the questions that we would like them to at least try and answer beforehand, sometimes for the panels, you know, not all of the questions will apply to everyone on the panel but, you know, to the best that they can answer those questions that we provide them within their five minute testimony.

We try to usually limit the number of people on a panel to about five people. Once all five people have presented within their five minutes that their allotted, so if you figure five people each have five minutes that's 25 minutes and then we open it up to questions from all of the Workgroup members so if we do it virtually you all will have the opportunity to raise your hand and ask questions and it really becomes a discussion and as Gayle and Deven have just mentioned that typically is where we get the most from the hearing when we're able to dive a little bit deeper into what they've already presented in their hearing and testimony and, you know, ask additional questions and that typically has been what works.

We do ask for them to send a written testimony in advance but we don't require it. A lot of these people are very busy so, you know, just having them testify is very helpful. Obviously we tell them how much we appreciate the written testimony and we send that in advance of the hearing so you all have the time to review that and will help you come up with questions to ask the panelists. So, I don't know if that's helpful but I thought I would give that background.

W

Thank you, that's very helpful, thank you.

M

It's very helpful.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes, thanks, Michelle.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

And one other, this is David, one other thing that a number of times people will submit as part of their written testimony much more extensive coverage than they can squeeze into the five minutes which is also very helpful.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, no it is and it's particularly helpful when folks inevitably end up feeling like they have to use some of their five minutes to present some introductory material about who they are.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

We should warn them against that.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

I know we do always David it's just...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

I know...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

It works for some and doesn't work for others.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yes, I know.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

But still it sounds like we're circling in the right general direction but just trying to figure out, you know, maybe the dividing lines are not...of the panels are not in exactly the right place and we might choose to bucket them slightly differently.

Was there anybody who had a sort of substantive topic or issue that they...that is health big data related either opportunities or unintended consequences, side-effects, etcetera, obstacles that they didn't see on here at all?

Gilad J. Kuperman, MD, PhD, FACMI – Director Interoperability Informatics – New York Presbyterian Hospital

This is Gil Kuperman, just...and this maybe a little peripheral but, you know, I think this is great about where the puck is today.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Right.

Gilad J. Kuperman, MD, PhD, FACMI – Director Interoperability Informatics – New York Presbyterian Hospital

You it's such a fast moving field that, you know, I don't know if there is any, you know, research areas that are on the horizon that maybe bringing us new problems, you know, in 12 months or 24 months, so, you know, I just don't know if maybe, you know, some kind of, you know, forward looking things, you know, techniques or methods that, you know, may bring new challenges, you know, I don't know exactly how to get at that, but that was just kind of...just one thought that I had as I was looking through this.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, that's a really good point Gil and it actually is reminding me of a conversation that I had earlier this morning with ONC where they, you know, specifically want us to sort of project a little bit into the future especially around this learning health system in terms of sort of what the needs may be for not just near-term analytics but what might be both doable and/or desirable...

Gilad J. Kuperman, MD, PhD, FACMI – Director Interoperability Informatics – New York Presbyterian Hospital

Yeah.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Within the next 5 to 10 years. It's a little harder to sort of get at that right now but certainly, you know, to the extent that maybe there are some sort of...

Gilad J. Kuperman, MD, PhD, FACMI – Director Interoperability Informatics – New York Presbyterian Hospital

You know...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Vanguard systems that are already doing some types of analytics that while might not be widespread they're showing some promise and we want to make sure that others can do them as well or that more of that type can be done. Some people put predictive analytics in that category, you know, maybe there is enough of that going on that it's a near-term need or activity versus one in the future. But, you know, I would look to all of you to help...I'm probably the least able to have a crystal ball on some of this stuff.

So, you know, if there are some specific sort of areas, issues that we need to sort of include in an exploration that is not just near-term but here's what we want to be able to do in the future and whether it's because no one's doing it now or because some people are doing it but not enough people are doing it.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

This is Linda Kloss...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

The...

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

And I think there is, you know, certainly a whole tool of advanced methods that are of interest even beyond what we are thinking of as predictive analytics today. But one of the general topics that doesn't seem to be here is the analytic workforce and I think that needs...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Well, so, I'll tell you one reason why, is because at least for the Privacy and Security Workgroup that provides a bit of a limiting factor to our consideration of these issues.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

But I think there is a privacy and security dimension...

W

Although I wonder if, you know...

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

In terms of training.

W

Training the workforce...

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Yeah.

W

In...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Hold on let Linda finish.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

In stewardship practices, right, that's where I was heading.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay. Now who else...

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

It's not the size of the workforce but with the...what we've seen is as analytics and big data...I mean, it's a much broader pool of people doing this work that may not have any of the foundational understanding of privacy and security dimensions.

W

Yes.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay, whoever I interrupted before did you get your point in? I'm sorry.

W

Yes that was the point.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

This is David, I was...

W

That was the point, yes.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay. Go ahead David.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

On the big data concerns topic I sent you a link earlier in an e-mail today when I wasn't planning to join the call about, you know, sort of a low grade rumble that's emerging around some of the limits of big data that are not necessarily recognized by many of the people who are jumping into the field, the trait big data winter being coined sort of...to the AI winter that followed the early burgeoning fascination with AI in the late 80s, so the real issue there is that we may attribute more power to some of these techniques than the really deserve or conversely don't underestimate the range of Arab "R's" that are associated with some of the big data predictions and conclusions. So, there are a few people out there that we could probably tap to talk about that on that discussion on the concerns.

Mark Sugrue, RN-BC, FHIMSS, CPHIMS – Chief Nursing Informatics Officer – Lahey Hospital & Medical Center

This is Mark Sugrue again, I had a similar thought in terms of, you know, the old adage "data rich information poor" and, you know, when I think about big data I think we can end up with rich or richer data and still not have good information if we don't do it the right way. So, I concur with that general theme of that.

M

And Deven, does that fall within our purview if we're talking about quality of predictability or quality of predictiveness or the value of the inferences versus the privacy and security issues? I think those are significant harms they're discussing I'm just wondering if it's within our bounds.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

You know I think we probably if we're going to...I guess this is my sense, I'll be interested again to continue this thread of the conversation, you know, if we're going to have this sort of...some people testifying about what the opportunities are, you know, rah, rah big data I don't know that it necessarily hurts to have a few, you know...

M

Okay, good.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Presenter who says, look, you know, there is excitement but we...let's not let the hype get ahead of the reality.

M

Right.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

You know...

M

Well, I think there are...I think those two go well together and actually the ones who are good about talking about the opportunity will in fact talk about the current limitations and because of the quality of data and the inability to vet out some of the confounding variables. So, I think those should be paired together pretty closely I think.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, but at the end of the day, you know, we really do have to aim at scoping out a set of issues that are relevant to our charge.

M

Right.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

I mean, one of the nice things about hearings and listening sessions is that we can get...we can go a little broader in order to effectively pare down in the right way but we don't want to have our initial universe be so big that we, even after these hearings, still have some trouble narrowing our focus.

David F. Kotz, PhD – Associate Dean of the Faculty for the Sciences – Dartmouth College

Well, this is David Kotz, I was thinking about this issue from perhaps a relevant point-of-view, one of the things that big data does is draw inferences from large amounts of data and sometimes those inferences are kind of obscure, you know, how did it come to that conclusion it's often difficult to go backwards and figure out why.

And if that conclusion is about a particular person and their health risks or their health conditions or their behavioral issues than that could cause harm to them because people or organizations might draw the wrong conclusions about them.

And in the privacy world, in the information privacy world, there is a concept that people should know what information is collected and stored about them and be able to correct incorrect information, it goes back to the fair information practices philosophy and I don't know if there is an analogy that we need in the big data inference world where people can contest incorrect inferences drawn about them or their health.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

That's a great question.

M

Love it.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Well and there are some good examples and case studies on stigmatization too of communities where incidence of disease in the community can impact property values and other kinds of consequences that...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yes.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Well, I mean, I think that that's exactly what...I mean, at least when we put these sort of initial topics together that's what we envisioned sort of coming up in the area...in bucket three which is the next page.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Right.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

I wonder Deven if, and I'm sure you've thought about it, this is David again, you could denormalize topic number three into the other topics and just say, please address the potential limits and harms, and others. I mean, it would be...you know we'll ask those questions of those panelists...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

I'm a little worried that we won't get the right people.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

You know I do want in panel one to have some folks that are doing, you know, some interesting things...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

The cheerleaders.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Right and there may be a little less focused on these issues than some other...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

That's a good point.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

That's the problem with asking...not that we couldn't in Q&A ask anybody to address the, you know, opportunities and obstacles, and issues but I worry if all of the issues are being asked to be surfaced by the proselytizers...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, yeah, good point.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

We might not get the right testimony back.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Yeah, good point.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

And the opposite would be true too right, if we asked, you know, the folks who are largely raising red flags about this to talk about the opportunities we'd get more limited testimony there as well.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Therein lies our charge.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Therein lies our charge.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Find the right panelists.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Find the right...right exactly. Let's turn to slide seven just because we have sort of under discussed these two topical areas although threads of these issues have popped up in some of our other conversations.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

This is David, I really love that we've included that topic and you know Deven that it's near and dear to my heart this de-identification question and the discussion about prohibitions on re-identification and use limits I think that's a really important subject.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yeah, well and I wonder if this is the candle and we don't have to decide this now but I'm just thinking out loud that, you know, to sort of fold in the work that...hearing more about the work that NCVHS has done with respect to the toolkit.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

I think that's...I think this is where that belongs, this is Linda, yeah.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

You know and I know that, you know, the leadership conference on civil rights has been taking this issue on, the issue of concerns and the possibilities for discrimination, I wonder if they've gotten to the point of discussing, you know, possible protections, you know, which then leads me to think, to recall that at least under current law, you know, we probably need to talk about what the Fair Credit Reporting Act might or might...

M

Yeah, I was just...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Not cover.

M

Yeah, I think especially if you're talking about inferences. I mean, I think that's where a lot of the socioeconomic data is going to be...stuff is going to be there, where a lot of the health inferences are made.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes.

M

Our friends Jennifer and Sheila could do a good job with that at Axium.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay. All right, well we have...so a couple of common threads that have come out here include some suggestions about where to draw lines in terms of how we break these panels up a little bit and make them more manageable over a two day period some suggestions of stakeholder groups or areas to target and also the idea of a list of questions which I like because it does really help focus the testimony.

Should we spend some time, since we have it on the call, today thinking through, you know, sort of what those questions would be and if I go back to, you know, sort of the opportunities slide we have, you know, discussion about trying to understand both...to try to spearhead some speakers that have looked at the landscape out there and can speak to generally, you know, what's going on in the field whether it's folks from AHRQ or ASPE or even an academic or two but also maybe having some folks from specific area...you know, from some of the specific data types genomic data for example, PCORI, a social networking site, mobile Apps device, you know, would we...since we're trying to get the opportunities and, you know, potential obstacles do we want the same set of questions to sort of go to everyone but just ask people to emphasize different things for purposes of the panels? What are people thinking?

I mean, it wouldn't be that hard to come up with a broad set of questions that we ideally want to have answered and they're sort of reflected in the topical choices that we've made here.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

I think it's...I mean, having done, you know, listened to many of these panels and having participated on a few it's usually pretty obvious which questions are relevant to use so if you see one and it just doesn't make any sense I think most people are pretty comfortable, you know, not putting any energy into that one and focusing on the more relevant ones.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Right.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

So, I think that works out okay in practice given the five minute limitations people are pretty parsimonious.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Right, right.

Gilad J. Kuperman, MD, PhD, FACMI – Director Interoperability Informatics – New York Presbyterian Hospital

Yeah, Deven, Gil Kuperman here, you know, I think with, you know, with each of these there may be some issues that are domain independent and then there may be some issues that are domain dependent and, you know, with each of these, you know, as the amount of data that, you know, is being managed increases there is, you know, there are new opportunities and there are also new challenges, and, you know, so, maybe asking the panelists to speak about those and say, you know, which, you know, which do you think are relevant, you know, purely to the, you know, amount of data that you're dealing with and which of those are relevant to the specific domain that, you know, your particular area is focused on.

And so, you know, maybe, you know, folks could tease it out by just, you know, the general nature of the problem but also if, you know, somebody is working with genomic data they may have that or if they're working with, you know, credit data they may have that, so I don't know, I don't know if that's one way to kind of try to get a variety of sets of comments.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

This is Linda and I think it might be useful to extend a question asking for, if they can, to give an example of an issue that has, a privacy or security issue that has presented itself and how they've dealt with it just to begin to gather some of these anecdotes that maybe very useful to us.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes.

Gilad J. Kuperman, MD, PhD, FACMI – Director Interoperability Informatics – New York Presbyterian Hospital

Yes.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Good point.

M

The one thing I'm a little concerned about Deven is our two day session, two afternoons, I would really hate to have, you know, a conversation about opportunities on one day and a conversation about harms the next without the two groups mingling if we're really going to have speakers that are apart from that. So, to the prior comments I think that's what I'm hearing a little bit is that we need to at least intersperse enough of each so that we're having a more robust conversation.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay, interesting.

M

Well, I mean, you said, you know, the idea that if we have a bunch of people talking about opportunities, you know, the opportunities typically would then trigger risks associated with those opportunities and if they hear harm they may be able to counter what the opportunities are to counter the harm.

And so having folks who are focused only on harm or who are focused only on opportunity seems to me to not be the ideal circumstance.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

But how to you do that...

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Maybe we should...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

And not have this thing get carved up by domain?

M

Yeah.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

We could stage a debate.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

What?

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

We could stage a debate, I'm just kidding, but...

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay.

M

I mean, you know, maybe that's the work of the committee, right, maybe that's the work of this Workgroup is after you hear is to just kind of summarize and then have the, you know, next level of conversation is more pointed around the issues that have popped up and having a deeper exploration around that maybe that's how we address it.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

You know and I guess the other thing would be just to, you know, rather than trying to like...say we have four hours on the 5th and four hours on the 8th which, you know, for our west coast friends we are trying to scope this out for the afternoon so we're not getting you up out of bed too early. We, you know, rather than having, you know, two panels or three panels on one day and two on the next or three, you know, that we essentially try to do four panels on each day and just intersperse them right?

M

Right.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

We have opportunities and obstacles, and issues on both days but we don't try to divide it up by, you know, type of data or specific industry of data collector or data user but instead, you know, sprinkle some examples throughout but then on each day we have both the positive and the negative but, you know, we might need to reserve some time on the last day for the current law piece or we start with current law. I don't know that we need current law in two days.

M

Yeah.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

I think that's the best way to approach it Deven.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Yeah.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

I had not thought of that but it will provide people with a lot more variety in terms of the discussion on both days it's not segmented into, you know, here's the pro and here's the con and then we wrap it up with law.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Yes.

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

I really like that, this is Donna, I really like that idea too.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

I do too.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay, good one for those of you who suggested this, Stan I'm going to give you credit and Linda.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

So we could start day two with law and just get that on the table.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes. Okay, all right, I think a plan is starting to take shape. One of the other things that we hope to get from you today is some suggestions for people to testify and it's interesting we have on prior calls had in the public portion of our meeting discussions of particular individuals to tap, you know, which we certainly can do on this call as well, but people are also welcome to off line send suggestions to us.

So, for example if there is somebody that you want to check with before you overtly suggest them you have an opportunity to do that because we really do need to start, you know, getting a more firm description of the panels and what we're doing and building a question list and then start identifying the people that we're going to target very soon if only because we have a very short amount of time to try to pull this off. Anybody have any additional thoughts?

All right well what it sounds like Stan and I, and the staff need to do are to, you know, take the very good suggestions that came out of the discussion today and put together a little bit more specific of a plan for those two days and maybe come up with a broad draft question list which we will circulate to all of you by e-mail. We don't have another call of our working group until...MITRE can you or Michelle can you remind me of when that is? Anybody? All right, I'll look on my calendar.

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

Sorry, Deven...

M

It's not the 24th?

W

The 24th.

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

It is the 24th at 2:00 p.m.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay, great.

M

Okay.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Thank you all.

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

Deven?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Yes?

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

We could set up an administrative call to talk about the hearing. Actually that would be my preference especially if we're going to talk about names and things like that.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay.

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

We might want to think about doing that and that's something that we can do within the FACA because it's just purely a planning meeting.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay. I'm just a little bit worried that we probably need feedback from people if we're going to be inviting...we need feedback from our Workgroup members if we're going to be inviting people to give presentations on the 5th and the 8th probably sooner than the 24th as opposed to turning that call into...but we could turn that call...I think probably what we need to do is to try to make some progress off line by e-mail and then do a planning call on the 24th. Does that make sense Michelle?

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

Yeah, I mean, we can try to do it, you know, the week of the 17th and see if we can find a time that would work for most people if you prefer not to take away from your scheduled calls.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Right, right. I mean, really what we need to do is plan and we can always see if we can get something scheduled for the 17th for those who are unable to...for those who are able to make it, since we're not voting we won't worry if we have less than full participation, but probably also do some work off line to try and make some progress in the interim. Does that make sense? So, keep an eye on your e-mail inbox. Michelle let's work to try to get a planning call that week of the 17th.

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

Okay.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

And we'll just leave the call on the 24th as it is for now. That's the week of Thanksgiving we may not have full participation anyway.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Very good, so you want names first?

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Names and questions.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Okay.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

How about that? And then Stan you and I will work to work with MITRE and ONC to come up with a plan for the two days in terms of how we divide this up panel-wise.

Stanley Crosley, JD – Director, Indiana University Center for Law, Ethics & Applied Research (CLEAR) in Health Information – Drinker Biddle & Reath, LLP

Okay, that works.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay. Other thoughts? Okay then I think we're at a stopping point for now. Michelle do you want to open up the lines?

Public Comment

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

Sure, operator can you please open the lines?

Lonnie Moore – Meetings Coordinator – Altarum Institute

If you are listening via your computer speakers you may dial 1-877-705-2976 and press *1 to be placed in the comment queue. If you are on the phone and would like to make a public comment please press *1 at this time. There are no public comments at this time.

Deven McGraw, JD, MPH, LLM – Partner – Manatt, Phelps & Phillips, LLP

Okay, terrific, thank you all for a really great discussion. Keep an eye on your e-mail inboxes and look forward to talking with you again soon. Thank you.

M

Thanks, all.

M

Thanks, Deven.

M

Thanks.

Linda Kloss, RHIA, CAE, FAHIMA – President at Kloss Strategic Advisors, Ltd.

Thanks.

M

Bye-bye.

David McCallie, Jr., MD – Senior Vice President, Medical Informatics – Cerner Corporation

Bye-bye.

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

Thank you.

Public Comment Received During the Meeting

1. Thank you for making these sessions available to the public. You have a daunting task. Understand how important our group web conferences are in our UW informatics program.