



**Health IT Standards Committee
Precision Medicine Task Force
Final Transcript
April 13, 2016**

Presentation

Operator

All lines are now bridged.

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

Thank you. Good afternoon everyone, this is Michelle Consolazio with the Office of the National Coordinator. This is a meeting of the Health IT Standards Committee's Precision Medicine Task Force. This is a public call and there will be time for public comment at the end of today's call. As a reminder, please state your name before speaking as this meeting is being transcribed and recorded. I'll now take roll. Andy Wiesenthal?

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Here.

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

Hey, Andy. Leslie is travelling today, so she is not with us.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Hi.

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

Andrey Ostrovsky?

Andrey Ostrovsky, MD – Chief Executive Officer – Care at Hand

Here.

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

Hi, Andrey. Betsy Humphreys? Christina Heide?

Christina Heide, JD – Senior Advisor for Health Information Privacy – Office for Civil Rights

Here.

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

Hi, Christina. David McCallie is not able to join us either. Dixie Baker?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I'm here.

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

Hi, Dixie.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Hi.

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

Eric Rose?

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Here.

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

Hi, Eric. Gil Alterovitz?

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

Here; hi there.

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

Hi, Gil. Jim Breeling?

James Breeling, MD – Director, Bioinformatics, Office of Research & Development – Veterans Health Administration

I'm here.

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

Hi, Jim. Jon White is not able to join us. Joyce Sensmeier?

Joyce Sensmeier, MS, RN-BC, CPHIMS, FHIMSS, FAAN – Vice President, Informatics – Healthcare Information Management Systems Society

Here.

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

Hi, Joyce. Ketan? Mary Barton? Matthew Might?

Matthew Might, PhD – Visiting Associate Professor – Harvard Medical School; President – NGLY1 Foundation

Here.

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

Hi, Matthew.

Matthew Might, PhD – Visiting Associate Professor – Harvard Medical School; President – NGLY1 Foundation

Hi.

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

Mitra Rocca?

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

I'm here, present.

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

Stan Crosley? Steven Keating?

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

Hi, here.

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

Hi, Steven. And Terry Rauch? And I'm sorry, I skipped over Maya because you were no longer the staff lead. Maya is here.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

I'm here; hi everyone.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Michelle, this is...

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

Is there anyone...

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Sorry, this is Mitra. I notice on the new slides you sent off Jon White, Betsy Humphreys and my name is not on the list.

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

Umm, it should be on the list but we can check. There...I think it goes to a second page now, but maybe...I'm pretty sure that you all were on, but let me check.

Mazen Yacoub, MBA – Healthcare Management Consultant

I'll...

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

Is there anyone else on the line?

Mazen Yacoub, MBA – Healthcare Management Consultant

This is Mazen, I'll double check and if it's missing, I'll add it back in.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Thank you.

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

Okay, with that I'll turn it back to you, Andy.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well thank you. As Michelle has noted, Leslie won't be with us today, she's traveling and unable to call in and so she and I are kind of channeling each other. And there are a number of other people who extended their excuses, so we'll try to think hard and represent their thinking, particularly David McCallie, who actually was kind enough to submit some comments in advance so for the rest of the committee, when he reviewed the material he gave us some comments and we'll be able to incorporate those so everybody can hear them.

I have no other specific opening remarks other than to say we are proceeding remarkably quickly for a government body, and that should be pleasing to everyone. And I think we should therefore continue with that pace and move on to our work plan review. Do we have to approve minutes or anything like that as a workgroup, Michelle?

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

No.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I don't think we've ever done that. I didn't think so. All right, let's move on to the work plan review. And everybody's used to this so we can breeze right by it. There's the list and everybody seems to be on it.

Here are the statements about the role of ONC in the Precision Medicine Initiative and we've seen these a number of times, so I think we can move past them. And here is our charge, and again, this is just for the purposes of reinforcement; we've all seen it so let's move along.

And here is where we are in our work plan. So we're about halfway through the work that we have and others have set out for us. And so we're in the beginnings today of our discussion of draft recommendations, and I hope that everybody's had an opportunity to read the material in advance and we have to face ahead a Joint Health IT Committee meeting of the Standards and Policy Committee next week. And we are going to attempt to bring some of these draft recommendations to that Joint Committee, and then we'll continue to meet to finalize our recommendations after getting comments from the Joint Committee and from elsewhere.

So, let's move past this; and again, this is a slide that we've seen before, but I think it bears some repetition. This is the way we are looking at the path...the interoperability pathways that are critical to the Precision Medicine Initiative. And so we've segmented this into near term, mid-term and long term recommendations. The near term is intending to focus everybody's attention on electronic health data first; things like labs, meds, the stuff that we know all of us with experience in the arena, and all of us have it, is pretty readily available.

And so the workflow or the information flow, I should say, is obvious in that first swim lane. As a consultant over the last six years, I've learned that's a new phrase, that's a swim lane, the top one and the middle one is another swim lane. So, the individual participants' portal will include some information, the health plan or the health plan organization, the practitioner organization will include information and that will flow, for example, into the NIH precision medicine cohort.

Mid-term focus is again enabling data gathering from other sources, other than the easiest low-hanging fruit sources that we're all used to. So in some cases, some laboratory information that's a little less connected. Things from the PBMs, claims and retail pharmacies, and again, coming into the cohort; and then finally things coming back, so good feedback to the patient and to the practitioner. So let's move on past this.

So near term recommendations; there's some detail here and the intent is that we would recommend leveraging the existing consensus-based data export format that we already know about. We already have it, is in wide use, to facilitate mapping and contribution to the cohort. And that examples would include the ones listed in those bullets, I need not repeat them; we've talked about this. And there are some benefits and limitations of data models that are out there. There is ongoing work to refine them.

And for individual data, we would recommend using a consistent FHIR-based API; things that are being done already in Sync for Science and recommended by Argonaut. And there may be FHIR resources that are new that would be necessary, and there may not be. Any comments on these slides so far?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah, Andy I have a comment; this is Dixie.

**Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP;
International Health Terminology Standards Development (SNOMED)**

Yes, Dixie.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Umm, I'm not sure what they mean by format; are they talk...are we talking about the data model and if so, these are different, at least...well, there are three different data models we have listed there.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

But the DAF uses, you know FHIR, HL7...and the PCORnet data model, the CDM and NCI has its own data model so I'm not sure what the data export format means, you know, and how those could be examples? So I guess it's a question.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I guess, I think they do data models, but I'll ask in general if anybody else has that question or do we need to d...how we should be discussing it from Michelle or Mazen. So hearing nothing...

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

I'm sorry, I don't know.

Mazen Yacoub, MBA – Healthcare Management Consultant

This is Mazen Yacoub...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I'm sorry, go ahead, who's that?

Mazen Yacoub, MBA – Healthcare Management Consultant

This is Mazen. I think some of that is a product of some of the input that David McCallie had sent.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right.

Mazen Yacoub, MBA – Healthcare Management Consultant

And he had raised some questions around, or perhaps it was also I think we received some written comment from Josh Mandel and they talked about exports, mapping of data exports versus prescribing a data model because the various HPOs and participants might have their own internal data model that they're working with which are largely influenced by the vendors whose systems they may use, which may vary from participant to participant.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

So that's exactly my question because the, and I didn't...the data export is always going to be the EHR data, you know data model. So it's most likely going to be FHIR, because that's what's likely to be in the EHRs. The EHRs will not be exporting, for example, the PCORnet CDM or the NCI data model, you know, I think we've mixed apples and oranges and tangerines all in this recommendation. Because it's not clear

what format we're...what we're mean by term format, and as the speaker just said, yeah, the export data model, you know, will be the EHR data model and it's not likely to be any of those. I think both of those are the key questions.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Umm...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay, so, go ahead...who's...

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Andy, this is Eric. The...apropos this, the confusion I had looking at this slide is why there's a distinction made between that path from the HPOs EHR to the NIH and the format of individual data to NIH and I'm wondering why they would need to be different. Is it because one would be sending data on multiple individuals in a single transaction and the other would be on a single individual? But I wonder if there really...is it the case that there...that those needs be different?

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well I, I mean I don't...I won't answer that...I don't think they need to be different, I think they are different. And it's because individuals are going to be collecting data and uploading it either to a portal or funneling it through a portal to something else, to an App in a variety of ways from their own devices, from just personal data entry and we can't make assumptions that the format right now, that those data models are in any way comparable, not to mention identical to EHR data models.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Mm; well the data model in question here would be not the data model of the native App that the data's coming from, it's the data model implicit in the standardized message, you know so, I mean...of course all the time they reconfigure or transform their da...how the data is natively to be able to export in standard format, like a CDA.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right. So understood and I mean, we just don't know what Apps are going to do, right?

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Mm-hmm.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

So we...

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

We're trying to make recommendations though.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

(Indiscernible)

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

We sort of do, I mean right now we know what Argonaut is exporting and we know that the Sync for Science is using the Argonaut. I mean, and they're exporting the same data the EHRs are producing. I mean, and while anticipating FHIR.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well, I mean, so we could recommend that this be more restrictive and say, if it...if the App, whatever it is and it may not be Sync for Science or anything that Argonaut has established, it may not follow anybody's, you know, patterns or standard recommendations and may just be some kid with Red Bull and pizza building an App that people decide they'd like to use. Umm...

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

But they're ex...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

You can say, well we're not going to do that.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

They're exporting data from...the Apps are just retrieving the data from the EHRs.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right and then they're going to send it somewhere and the format they use may or may not be compliant.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Well they'll send the same data that they received though, right?

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well and they may screw it up.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Despite what you're saying they may transform it into something...I think the transformations and mapping shouldn't be expected to be done at the EHR end, they should be done by PMI.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Agreed.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

Hey guys, this is Maya, sorry I just wanted to jump in really quickly. Umm, one thing that may be helpful to focus this conversation is, umm, as I think you guys are aware, we don't actually know...I think NIH is

still going to think about how to handle this issue. One thing that might be helpful in terms of the recommendation here is just to identify different options, right? So to Dixie, to your point of like who kind of does the mapping, what are the pros and cons of where it is done? You could identify different options of like where you could do it and what will be the consequences of doing it that way. Does that help?

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

Just because like that kind of decision of where the mapping will be done is TBD.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

And I think it's going to be TBD after this afternoon, too.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

Correct.

Andrew M. Wiesenthal, MD, SM- Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Umm, because there are several different possibilities and they all have benefits and costs associated with them. To impose that on the NIH, umm, it might be logical, but it probably is extremely complex and costly to do it that way, rather than to ask that the sending systems to do it.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Umm...

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I can't even...providers would do that though, Andy.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Pardon me?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I can't imagine that providers would take that on, that all of sudden all the certification standards would change and say, if you're exporting it to a research...to NCI, use this model. And if you're exporting it to PCORI, you know use this model. And if you're going to export it to PMI, use this model, you know I think it would be...it's unrealistic and unfair to expect provider organizations to export data anticipating the data models of the ultimate data user.

**Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP;
International Health Terminology Standards Development (SNOMED)**

Right and so, you see if I were a Czar, and I always resist using that metaphor because everybody knows what happened to the actual Czar; but if I were Czar and was in charge until my family and I were slaughtered, you know I would say that there should be a data model for the country for everything, but that isn't the situation.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah.

**Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP;
International Health Terminology Standards Development (SNOMED)**

So figuring out how to normalize data and where the best place is to do that is actually not so mu...technically somewhere you have to do it and it...wherever you do it technically it's sort of the same problem, right? Its where is it most efficient and least costly.

**Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School;
SMART/FHIR Genomics Lead**

So I have a comment that might be useful here; this is Gil Alterovitz here.

**Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP;
International Health Terminology Standards Development (SNOMED)**

Hi, Gil.

**Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School;
SMART/FHIR Genomics Lead**

Yeah, hi. So there's a few...it seems like there are a few that are agreed on that, you know they may have different uses, like is it...but there's a concern that the...there's a couple of potential standard candidates, but it may grow over time, can we maybe limit and say, you know these are a list of standards, you know maybe not pick which one, but at least that way we recommend...we have a list of a few and it won't grow more.

The reason I'm thinking about this is when I think about, you know in genomics there aren't as many and if you limit the number of options now, then it won't grow and we won't have this issue come up, you know in a couple more years, you know in other areas that are kind of new. So by limiting the choices, it sort of allows us to constrain the problem potentially.

**Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP;
International Health Terminology Standards Development (SNOMED)**

So I like the last word, Gil; I think that's the right ap...to me, it sounds like a very helpful approach and that is, we don't necessarily need to stipulate, we can make some recommendations about which ones would be on our short list, but that there should be a short list, that there should be a constraint...

**Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School;
SMART/FHIR Genomics Lead**

Right.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

...is an important recommendation.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I'd like to go on record it's my recommendation is that they export it in a standard EHR format that the recipients can anticipate.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

This is Gil, I support that, too actually. It's just the data models that people may have at the end in their system may be different then they'll need to translate, you know.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

But I think they know that, they even have translator...you know that, Gil.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

Right. Oh yeah, yeah, no, I'm totally supportive, I'm...I...

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yes.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

...just trying to rephrase it.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Eric does that...

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

This is...sorry.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Go ahead.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

This is Mitra from FDA; so I...the PCORnet I was wondering, we can add the word common data models because like I am familiar with Sentinel's common data model so all the data partners take their local data and bring it into this common format and one of my tasks was to make sure they use the standard and controlled terminology and when they export, they use CDA.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah so again, a set of constraints.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Yes, that's right.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

And also CDA is supported under FHIR, FHIR allows for...

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

That's right, yes.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

...export of CDAs.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Yeah, this was before FHIR, so.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

It's consistent; I mean FHIR supports CDA document transfer...

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Ah yes, that's right.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

You're talking about two different things; I think she's talking about CDM and you're talking...

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

Oh, I'm sorry.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

No, no. no, CDA. Oh no, that was...one, the first comment was to add the word common to this slide, because it's not data model, it's common data model because they spend like within...at Sentinel I've seen how...

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

...like data partners which are these large health plans, but some of them have EHR, like Kaiser Permanente, they spend like, I don't know six months to bring their local data into this common format. Then on the common format, we always push them to use then EHR the standards that are mandated by ONC as part of EHR certification; for lab use LOINC, for diagnoses use ICD-9, ICD-10, CPT codes. Now we are moving to SNOMED CT and RxNorm.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

All right. Well, so...

Betsy Humphreys, MLS – Deputy Director – National Library of Medicine

Andy?

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I'm sorry, go ahead.

Betsy Humphreys, MLS – Deputy Director – National Library of Medicine

Andy, this is Betsy Humphreys; I'm sorry I wasn't...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Hi, Betsy. Welcome; you're welcome, you didn't miss much.

Betsy Humphreys, MLS – Deputy Director – National Library of Medicine

So, in terms of all this, what I see if you were...it's, I'm in agreement with what everybody's saying. I'm looking at two parts of this slide; there's the HPO part and then there's the individual data part. And I think what I've been hearing people talking about is both at once, but...or maybe not. But I agree with what Dixie and others have said, that it seems to me that who's ever writing an API for individual whatever should in fact be writing it to a common export format required from an EHR.

Now when we're up here with what the HPOs are going to do in terms of transmitting large amounts of EHR data on many participants, at least it is hoped, to...in the PMI, then some of the things that are listed there begin to make more sense to me in terms of the output format. But of course, although there is interchangeability among them, in my opinion the most superior of the common data model formats is the one of the OHDSI Group, son of OMOP or daughter of OMOP. Because that one has the constraints to the control vocabularies and of course it has a huge amount of uptake around the world

and in the United States with literally, you know, more than 500,000,000 patients engage...represented in terms of people who can output their data in that format.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay. Michelle, are you and Mazen scribbling furiously, I hope?

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

Yes.

Mazen Yacoub, MBA – Healthcare Management Consultant

Yes.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay. All right.

James Breeling, MD – Director, Bioinformatics, Office of Research & Development – Veterans Health Administration

I would add that the VA is attempting to map its corporate data warehouse to OMOP.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Mm-hmm.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay. So we've had a lot of discussion here and I think what we'll have to do is take it offline a little bit and try to synthesize it, but if I can do that a little bit verbally. The expectation would be that everybody be constrained to using the EHR export format, if I'm saying this right, and that the recipients would anticipate that and have some work to do, depending on their internal data models to translate once they receive it. So I'll stop and see if anybody objects to my paraphrase.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Perfect.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Yes.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Perfect, I agree, that's exactly what I was talking...

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Yeah, yeah, it is.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Wow, okay, I'm retiring.

Betsy Humphreys, MLS – Deputy Director – National Library of Medicine

Obviously time to end this call.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

All right. I guess, I think we can move on then.

Joyce Sensmeier, MS, RN-BC, CPHIMS, FHIMSS, FAAN – Vice President, Informatics – Healthcare Information Management Systems Society

Andy, this is Joyce Sensmeier.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Go ahead, Joyce.

Joyce Sensmeier, MS, RN-BC, CPHIMS, FHIMSS, FAAN – Vice President, Informatics – Healthcare Information Management Systems Society

One other comment on top of your perfection; umm, I just want to say I think we all recognize that FHIR will be absolutely essential here with the individual data. I just think we somewhere need to acknowledge that it is still an emerging standard and it is evolving very rapidly and, you know using the word standard with that is a bit challenging because we're, you know we've gone just now to DSTU version 2 and there will be more iteration. So I just wanted to maybe put that as a comment behind the scenes of this slide.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I think that's an important footnote and I think the generic footnote would be there's an expectation that this is going to evolve.

Joyce Sensmeier, MS, RN-BC, CPHIMS, FHIMSS, FAAN – Vice President, Informatics – Healthcare Information Management Systems Society

Yes.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

It's not static.

Joyce Sensmeier, MS, RN-BC, CPHIMS, FHIMSS, FAAN – Vice President, Informatics – Healthcare Information Management Systems Society

Thank you.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

All right, other comments?

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Andy, this is Mitra again. On the details section on this slide, you have others question mark. Would you like us to add others, like Betsy like mentioned ODHSI or OMOP; I am actually on the Informatics

Advisory Board and also Sentinel; they are different models than PCORnet and, I mean Sentinel and PCORnet are the same, but ODHSI is very innovative and advanced, different model.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well, I think if there are important others let's, if you can rattle, if people can rattle them off quickly, that's fine; otherwise we can...you can submit them...

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

I have that information.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

...to Michelle.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Okay.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

All right, going once; all right, let's move to the next. So here, umm, our...as it says, the challenge is patient identification and then confirming that in a chain of information flow that doesn't have the patient directly in it, and where there's data resident in data stores for business reasons but that don't have anything now directly to do with patient care, how do we confirm that that entity still has the authority from the patient to release the data for this purpose?

And so ther...we've had this discussion and I don't know that there's a way of settling it, except to build some standard approaches to notification. And then workflows that surround, you know, the easiest thing is going to be if there's, let's say a PBM wants to release everything it has about a whole...a large swath of people and they need consent. They have perfect information, perfect contact information, they have perfect identity matching, exactly the right person gets the cons...gets the request for consent and they give an exactly clear answer, either a yes or no. With each one of those steps, of course, I think you all recognize that the likelihood of 100% correctness is reduced at every level.

So what do you do with all the stuff that falls outside of that exactly perfect workflow? And I don't pretend to know the answer but I think some policy rather than a standard is going to have to evolve here. And I'd sort of throw that question open to the rest of the group; is this really completely about standards or is it more about what to do when the standards have taken you to a certain point and you still have a question about consent.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Andy, this is Eric; I don't...one minor comment, doesn't this question also apply to the...on the previous slide, the flow from the health provider organization to the NIH PMI cohort?

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

It could unless as a matter of course they got that consent as a single time thing or they established their way of gaining consent for the release of patient information because it's their patient. So this is...that's

the difference; here these entities don't have the patients or they may be at least disintermediated from the patients, right?

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Ahh, well...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

That's what...that's how I see the difference.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

I think we're...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

So if I'm...I think about Kaiser, you know we always, when I was there, we...because our patients gave us consent to use their health information for the purpose of taking care of them, we could do all sorts of things without asking consent each time. When we wanted to use the health information for research purposes, we asked them for a specific project and then it didn't have to be repeated every time some transaction was engaged for that particular research project.

So, what I would imagine that Kaiser is going to do with this initiative is to develop a workflow around asking their members once, do you want us to submit data for the Precision Medicine Initiative? Here is some information about it, they'll inform them, they'll let them have a discussion and they'll give a yes or no answer and that'll be binding forever, until they withdraw it.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Andy, I think you're mi...that we're mixing two topics on this slide.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I think the main topic on this slide is really how to assure identity and record matching, and that's a totally different question from authorization and consent and permission. I think that this slide should really focus on identity, 'cuz that's really the biggest...that's the biggest challenge with it.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I actually think it's the biggest technical challenge, but it's not the biggest challenge.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Well I think this slide should stick to one topic because they're two different things.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I agree with you so we should separate it out. Let's talk about identity matching and knowing who the people are, exactly. And then when you know who they are, how do you get the authority?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah, and most of the...that's what it's about. It just is in that first bullet it added t...and confirm authorization; I think that confuses things. The rest is just about, you know well, the second one's about data donation. Its two different topics that should be addressed separately, I think.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay and I think that actually will help the discussion because, again for me there are technical issues and there are technical standard decisions to be made about identity. And there are some technical approaches to authorization, but really there will have to be a whole set of policies wrapped around authorization and what to do in the non-cut and dry circumstances. I won't call them exceptional circumstances because I think cut and dry will actually be the exception rather than the rule.

Anyway, so guys on the staff side, does that make sense to you? Can we take it offline a little bit, I think, and separate out recommendations related to identity and recommendations related to authorization?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Well actually reading down farther, it's even got completeness in there. I mean, there's...

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

Yeah, this is Maya, sorry, this...a transition and then I'll stop jumping in so much. But the actual point, the original goal of this slide was supposed to be about how do we get as close to a complete record for meds and labs and then I guess we added a third one about claims as possible, given that we're not going to get a complete med list or med history from just the EHR, that there are also other sources such as PBMs and retail pharmacies and other areas that would help PMI to create a more complete record for an individual patient.

After the...I think as a result of conversations that like Mazen and others on the team had with David and Josh, we added something about identity and authorization. So I agree completely, that's a totally other topic that should be devoted to its own slide, probably. But for the purposes of this slide...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well...

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

...we were hoping to kind of think about how can you, if you need med history, if you need a current med list, you need to know when something was filled; like what are the different data sources you

could get both within...what can you get from the EHR and what can you also get from other sources to give you a most complete picture.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well but, you know so Maya appreciate the clarification, or at least how it all got to where it is, but the point that David and Josh were making is precisely that you can't just consider, you know the goal is completeness or approaching completeness, that's the goal. But what complicates that goal are the issues of identity and authority.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

Sure, yeah.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Everybody knows where the data sits, I mean if this was related to identity or authority, it would be easy, let's go...the PBMs, let's go to the retail pharmacies, let's go, you know wherever we think it sits and pull it all in. And that would be easy, relatively speaking.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

Yeah, so I think the goal of this slide was to identify those different sources, but I think to Dixie's point, like running through all the potential recommendations that this group could have in terms of identity, should...is enough content to take up a different slide, for the purposes of logistics. So I just want to determine what agreement to that point. Not necessarily taking that bullet out of this or taking that, you know the importance of that away from this but, kind of acknowledging that it's its own topic as well.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay. All right, other comments on the content here once we've...now that we've settled that.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Yes Andy...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yes Eric, go ahead.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

This is Eric. So, as far as identity goes, what about proposing a unique person identifier in the context of the PMI cohort and utilizing the, you know person identifiers are not the be all and end all for identifying people in healthcare data and yet, you know the idea of a national health identifier is of course going to be controversial one. And, you know if we...is it...could the task force say, we recommend that there be a unique person identifier for the PMI cohort and that that be made available to members of the PMI

cohort, to people who going to use...be responsible for sending data back and forth, and that it be utilized in...as part of the approach to patient identification.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay, any discussion or questions for Eric about that? Would you include that as part of the consent, as a policy issue telling people, we're going to create a unique number for you; is that okay with you?

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Perhaps and it might end up becoming a volunt...ad hoc voluntary national health identifier. People might join the PMI just so that they can get a bloody...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

They could get one.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

...health identifier that their...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well you know, I was thinking the same thing, it's a kind of Trojan horse isn't it. And...but it would be people saying, I...if you ask them and they said they did want it, I'm not sure how those folks with grave concerns about having a single national number could object to that and in fact, umm, you know you could ask them a further question which is, well now that we have this number for you for the PMI, do you want other people to use that number for the purposes of monitoring your health data or managing your health data?

So it's an interesting, it's an interesting question. I mean I would imagine for example, that the people building database are going to have the unique identifying number for every patient that comes into it. And the way you would discuss it with a person considering being part of the initiative would be to say, well you wouldn't want your lab data to be...or someone else's lab data who happens to share your family surname to be attached to your genetic or genomic data, would you. Anyway, so Eric, it's a great thought.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah.

James Breeling, MD – Director, BioInformatics, Office of Research & Development – Veterans Health Administration

So in fact in the VA we keep multiple codes, you know, one for the bio specimen, one for the -omics result, one for the survey data, one for the, you know data from the phenotype, the EMR and none of those codes are the same, but the master index is actually kept internally by an honest broker system that is heavily secured and guarded; just to, you know bring that up.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

So but you're saying that a veteran doesn't have an identification number?

James Breeling, MD – Director, BioInformatics, Office of Research & Development – Veterans Health Administration

No they do, but that's only linked to information from their EHR.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Not for purposes in other parts of the Veterans Administration like benefits?

James Breeling, MD – Director, BioInformatics, Office of Research & Development – Veterans Health Administration

Umm, no...well that's, yeah what I'm saying though is we're bringing in to our MVP Program is bits of other data that isn't identified with that other index; so their survey, their -omics data, their consent form is coded in a different way and the code is broken by our honest broker, but the rest of the VA has an EIN, an internal identifier number, yeah. But the MVP Program collects other data beyond that and that's encoded in the honest broker.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

So there is a number, the honest broker has it and nobody else has it.

James Breeling, MD – Director, BioInformatics, Office of Research & Development – Veterans Health Administration

Right.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

And what if you said to the veterans, would you like everybody else to have it?

James Breeling, MD – Director, BioInformatics, Office of Research & Development – Veterans Health Administration

Umm, our, well, we've done some market research; I don't know if we asked specifically that question but the gist of the market research we've done with veterans focus groups is they wouldn't prefer that.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

What wouldn't they prefer? They wouldn't want other people to have that information or they wouldn't prefer people to have that...to know who they are?

James Breeling, MD – Director, BioInformatics, Office of Research & Development – Veterans Health Administration

They wouldn't prefer to be identified necessarily.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right, interesting. All right, other comments here? So if I can summarize it...

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I'd like to know what...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

...I'm sorry, go ahead.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I'm just not clear what the topic is at this point.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well I was going to try to summarize the discussion to this point.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Okay.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

So for staff, I think we're having trouble here because there are essentially three different concepts floating through here that relate to each other but really will require each of them separate...a separate set of recommendations to the combined committees. One is, that drives it, as Maya pointed out is the desire to have much more complete information about an individual than is reflected in a single medical record alone.

The second, once you decide you desire that, and you desire it from sources outside of electronic health records, you have to identify, securely identify and match people. And when you do that, there are issues of consent to the use of data that's found in those other sources. So there are three threads and we've talked about the need for separating those threads for the purpose of making recommendations.

I don't know that there's anybody on this comm...work force who would argue against as much completeness as we can get at. Nor is there anybody who would suggest that we should not recommend some approach to identity matching, but that's probably outside the scope of this particular work force because there are lots of people working on identity matching and have done all that kind of work before. And the same is true for consent.

So, I think where it leaves us is, and then we had the discussion about making a recommendation around a unique identifier on the PMI cohort side, asking permission to create one and then making sure we understand what patients would like that number to be used for with the contribution that the MVP Program has such a number, but their customer sensing work came...helped them come to the conclusion that veterans did not want that number to be exposed, even within the VA at large and certainly not outside the VA. So I think that's what I've got thus far; does anybody have anything to add?

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Andy, this is Mitra. You mentioned matching patients might be out of scope, why?

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

For a Precision Medicine Task Force?

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Yes.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

That is kind of on a scope for some standard recommendation by a larger standards body, but as Dixie can attest to, you know the Standards Committee has worked a lot on that already. So I don't know that we want to make a separate set of identity matching standards recommendations.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

One thing we could do...this is Maya. One thing you could think about doing is just we could link to and reference the previous work that the Standards Committee has done in this area, to support...to make sure that there is something in the final deliverable of this group to that effect, but that you don't need to recreate the wheel for that.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

That's...exactly.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

Yeah.

Mitra Rocca, PhD – Associate Director, Medical Informatics – Food & Drug Administration

Because we have worked on that as part of FDA's Sentinel Initiative because we got to a point where we didn't have the big picture of the patient's data and we had to link it to registry data and other types of sources of data.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

So to your point Mitra, lots of people have worked on that.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

(Indiscernible)

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Dixie spent months working on that, if not years.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Actually, that was the...that's mostly the Policy Committee that did that.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

But I agree with Maya that we should reference it, because it's a huge, huge issue, everybody agrees, but obviously we don't get or nobody gets very far with it.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

I think it would be most helpful to kind of our other federal PMI initiatives to just know the resources that ONC has already kind of put together on this topic and we can add a section of the deliverable of this group around that, not have you guys do new work.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah, I think that's correct, I...because all we would do would be spin wheels yet again on the same issues. The new...the really unique contribution I think is Eric's, you know making a recommendation that there be a unique identifier and finding out what people would prefer be done with that, you know because it should be, you know, that should be a very secure way of attaching all the incoming information to the...from the phenotype to the genetic information at the level of the PMI. All right, so I think...

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

And I like the idea of attaching that with a consent to make sure that they know that that's happening, too.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah, just to ask them, you know...

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

...that's...we're going to do it, how do you want us to handle it?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah, yeah.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay. Thank you everybody. Let's move to the last swim lane. So this is the feedback loop. People get to see what's been...what kind of data and information has been generated and the provider organizations and practitioners get to see it. So our job, and it's...we noted that because it's probably important to retaining and maintaining interest of participants. And so how will this work? Umm, and we know that secular trends around desire for access to one's own health information are all going in the same direction. Everybody wants to see more and more of their information, to have more of their health record, more of the other things that are being collected that relate to their health, at least available for them to see if they want to see it.

And so, there's a set of recommendations in the last major bullet here and I was just going to stop; I'll summarize them, but people can read them. And again, leveraging existing standards, using experience of groups already out there to help us understand how to do this; and then basically making it possible for individuals to pull down their data in a way that they would like so they can review it; it's almost an apple pie recommendation. It's too easy.

Joyce Sensmeier, MS, RN-BC, CPHIMS, FHIMSS, FAAN – Vice President, Informatics – Healthcare Information Management Systems Society

Andy, and this is Joyce again, Joyce Sensmeier.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah.

Joyce Sensmeier, MS, RN-BC, CPHIMS, FHIMSS, FAAN – Vice President, Informatics – Healthcare Information Management Systems Society

Just would add existing and evolving standards for FHIR.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right, right, right; thank you. Others?

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

Hi, this is Steven again just making a quick comment, and I raised this the last time, too and I'd love to just have it on the record again that it states that this would be, you know the third long term point starting in 2017-2018 and I really think that it should be starting in 2016; like it shouldn't be number three, last on the list. Like I understand that you have to get one and two done first, but I think that...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah.

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

...this is the most important goal and it should not be last on the list, it should be first on the list and yes it can take a long time to do, but there should be people thinking about this right from the very start.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

And that's what the second bullet on this slide is about.

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

Exactly, yeah, but I just think it should like in brackets where it talks up top it says long term 2017-2018, just a very small part of changing it to 2016-2018.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay.

Betsy Humphreys, MLS – Deputy Director – National Library of Medicine

This is Betsy Humphreys. I think that there is obviously at the NIH great interest in returning data to participants as...possible and I think they are thinking in terms of this perhaps the earliest data they will be able to return until these...in place are actually information about how an individual may look related to the rest of the cohort in terms of data that they themselves supply. So if they are asking participants to respond, to provide data in answer to particular questionnaires or provide basic data about themselves or whatever, then they would more quickly be able to show back to the participants how their data on those things back up against data that's been submitted by other participants. But I think they are totally on the page with what you've said that they need to get data to the participants as soon as possible.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right, so I think just a friendly amendment is, we would take the date range on top and say 2016-2018 so that work begins today, the data release may not happen until there's actually data accumulated that makes sense to release, right?

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

Yes, that sounds great and just to start people thinking that, what are ways that we can leverage, even just returning individual data back to the patient so that they're incentivized; or connecting, like you have in the bullet points here, to Open Humans or PatientsLikeMe that ways the average public can get involved in that.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

You know, I'm put in mind of one of the ways that my own organization does training is to do it online and one of the ways that they have of making sure that people are, you know at least conscious is periodically they'll do a polling question in the middle of the online course and you can see the results immediately. There are polling techniques that allow the result display to happen right away. So this is not a...the amounts, the volume of data is of course going to be larger, but the strategy for simple display of certain kinds of demographic and medical problem data will be very, very simple things to tackle.

All right, let's go on to the next slide, please. And again we talk about privacy and security, other policy consideration. So what to do with research results as opposed to what to do with the results...the kinds of things that Betsy referenced which is simply essentially descriptive epidemiology, what's, you know what's the population look like and where do you...how do you compare to the population? That's one thing, that's not research. But research where there are still some open questions and the meaning of the data isn't clear has to be handled in a different way.

So, I don't think we have the answer to that; we're just raising the question. And then researchers are worried about their liability and what they do or do not need to disclose back. These are just open policy questions that we're making sure to raise. Are there any others that people are worried about?

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

Hi, Steven here again. Could we make a sample recommendation stating the difference between raw data versus analysis and that for research data, if raw data is provided back to patients, there should be no liability on the researchers; it's only the analysis. And so, because right now CLIA prevents even basic raw data from getting back to the patient if it's not done by CLIA certified machines. And I think there could be huge potential there if we can make the definition that raw data is different from the results of analysis and raw data should always not be limited from the patient.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay. Other opinions about that?

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

CLIA is now included in HIPAA so they do have to return the individual's data if they ask for it and a recent court case says it includes anything, all data. But this is different, this is research.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

Hey guys, it's Maya. So Steven's right, that's only if it's done in a CLIA lab that says HIPPA protection comes in with the right of access. However, I just want to flag that this is an issue that's very complex and should be...you could maybe do some sort of broad recommendation on this for this group, but I just wanted you to be aware that there are a lot of other people within the federal government that are very currently looking at this. So I don't want us to spend too much time on it because they can implement those areas where there's a lot of deep thought happening about how to make this work elsewhere.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yes.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I agree with that. Yeah, I don't think we should even make an...recommendation around this.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I just...I was just saying, we aren't making a recommendation we're just saying it's an important issue.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah, it is.

Maya Uppaluru, JD – Policy Analyst for Health Innovation, Division of Science & Innovation – Office of the National Coordinator for Health Information Technology – Department of Health & Human Services

Yeah.

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

And so yes, if we can't make a recommendation, then just stating the point that this is something that needs to be discussed, that there is right now a limitation on raw data going back and that needs to be discussed, because it could make a huge amount of difference if people can have access to raw data, even if the individual patient can't analyze it themselves, by them being able to possess it, they can take it and use it with other tools and things like that.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah...

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I agree with that comment. I also think that we should recognize and maybe make a comment about it that we know that in some instances individuals specifically want not to receive results data back and that they...that that is certainly their right as well.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah, and there...so there again there from a now workflow perspective, how do people indicate their preference? So there's a certain shared decision making aspect to the release or the manifestation, I should say, of information; I want it, I don't want it, I want it by certain channels or in certain forms but not in others. And it becomes, as we've all said repeatedly over the last five minutes, very complicated.

I also think there's a huge difference between data, lab data that is essentially binary; you've got something or you don't versus a number that sits on a range and that the range is variable from one instrument to the next, from one assay method to the next and within the same instrument and assay method, from time-to-time.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

So their permissions need to be granular; there are loads of people working on this as well.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yup.

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

I agree. I think all the data should be made available though, so even, I mean, every measurement you take has error associated with it and as long as the machine data error is reported, then it's all useful data still.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I agree with that.

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

There's always error.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

We all agree, so the question is, how do you represent it for people who are not expert, so that it has utility rather than just a piece of raw information that doesn't help them very much? So that's a separate set of questions.

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

And I mean, I think the answer comes back to exactly what you said which is, give people the option; so you can know, you can know nothing, you can know only results interpreted by your doctor, you know you have the full spectrum available...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Right.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yes.

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

...to the patient's choice.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yes.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Well and they typically, in my experience again at Kaiser is they...we attempted to actually do patient focus groups about what preferences people had and they had different preferences around different kinds of data.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Right, that's why granular is important.

**Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP;
International Health Terminology Standards Development (SNOMED)**

You know, so you want to send me my hemoglobin A1C and I'm a diabetic, you know just send it to me for God sake. My doctor doesn't need to see it first; I know exactly what it means. If on the other hand you've just biopsied a polyp in my colon and there is a result, there were very divergent preferences about how to handle that.

And it varied, unpredictably between people; some people wanted it because they thought it was the best way of sort of absorbing the shock and then getting over the shock and going back to their doctor and then having a conversation about what it means to have a pre-malignant polyp or a malignant polyp. And the other people said, no, I can't tolerate having that kind of information exposed to me in anything other than a direct face-to-face conversation.

**Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT
Media Labs**

And that's totally fair, I mean that's how it should be; patients should be able to determine what their individual preferences are and...

**Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP;
International Health Terminology Standards Development (SNOMED)**

Well, so that the po...but our recommendations should be that as Dixie has now said twice, that there has to be a way of controlling the channel, you know and the way the channel works in a very granular fashion so that if I have my biopsy done, and ordinarily I'm the guy who wants to hear everything and I don't want my doctor interposed between me and my results, I'm allowed to go in and throw a switch that says, not this one, I want a phone call that says you've got to come in and talk about this.

**Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT
Media Labs**

Yeah absolutely, on the same page.

**Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP;
International Health Terminology Standards Development (SNOMED)**

All right, enough said about that, at least by me. Any other comments?

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Andy, this is Eric; just about the bit on the previous slide about, umm, the participant should be able to get their data back from PMI. One of the things I think we ought to call out there is that it ought to be possible for them to get raw genomic sequencing data or genetic testing data, well particularly sequencing because that's, of all the information that they're likely to receive, that's I think unique in its likely usefulness to the individual for their health and health care for the rest of their life.

So I think it's one of the big perks of, you know some...I believe that, I could be wrong but I thought I heard that everyone in the PMI is going to get, or maybe a substantial number of people are going to get complete genomic sequencing and they ought to be able to get that back in a format that is as raw as possible so it can be analyzed 10, 20, 50 years from now. So I'd like, if the group agrees, I think that ought to be, you know, called out.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I'd be interested in...but I have a question of clarification; are you talking about in a computable format or just textual so somebody could read it.

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Well, it would have to be computable because by definition the raw sequencing data is not, you know, it's no good to anybody, I mean it...you could conceivably print it out, but it would be hundreds of thousands of pages and what I'm talking about is, and actually this is going to be also worth calling out because it would create unique challenges in terms of establishing data formats for this content. I think that some exist but they may be universal. But, yeah, basically getting your, you know your genomic data back in a computable format.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

I would not say back, I would say access to because a whole genome sequence is huge and what the individual wants is access to it and tools to be able to really...

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Yeah, sure, absolutely, I mean but access to and receiving it back, I guess yes, that's a fair distinction, Dixie. I just mean that I should be able to access it in a way that, well, I guess it's important that people be able to access it in a way that they can still access it after PMI goes away or, you know who knows the U.S. government goes away, I mean anything could happen in the next 50 years.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Got it.

Betsy Humphreys, MLS – Deputy Director – National Library of Medicine

Are you also talking about wanting to access it in the way of, I want it because I want to ship it to somebody else?

Eric Rose, MD, FAAFP – Director of Clinical Terminology – Intelligent Medical Objects

Yeah, I mean the use case would be...back in, way back in the teens I participated in the PMI and they sequenced my entire genome and it's now 2066 and I still can use that data in collaboration with software applications and healthcare providers and other resources to, you know help me manage my health.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

So Betsy, in answer to your underlying question, I don't think you actually have to ship it anywhere; you have to ship access information to it, right? It can still sit in the same storage place without ha...because as Dixie pointed, and Eric pointed out, it's...the file is pretty big and you don't necessarily have to send the file, you just have to create access to it for someone else.

Betsy Humphreys, MLS – Deputy Director – National Library of Medicine

Yeah, I get that. I think it's that if, however I would like to contribute that sequence to a totally other activity where they're building another database, then why shouldn't I be able to do it?

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

I suppose, I suppose you could.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah, you could. You give them the link to it.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Or, I mean the way, you know we...the country could decide that the way to do that is to simply as people "compile other databases" they just become subsets of this master database rather than having to build separate storage facility somewhere in caves, you know salt mines and so on.

Betsy Humphreys, MLS – Deputy Director – National Library of Medicine

Yeah, I think all these different ways abounded but the permission and the authorization chain becomes very short if it's my data and I have a copy of it and I give it to you...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yeah, exactly.

Betsy Humphreys, MLS – Deputy Director – National Library of Medicine

...as opposed to the other where I have to be validated that yes, you know you have a system where the person that I've given access to, somehow the fact that I've given access to and then they have to have access to this thing which is going to have a lot of security around it, of course. So the issue that I can just take a copy and hand it to you does, in fact simplify the problem of me providing access to the data to somebody else.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yes, it does.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

It also increases your privacy risk. I mean there are two reas...two big reasons why you really don't want to propagate copies of your genome and one is that it's so huge and there's no reason to be sending around all these data. But secondly is that you don't want a million copies of your whole genome sequence out there.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

This is Gil, yeah, I think I was disconnected so I just wanted to add this one thing that there's a difference between downloading and APIs, so and I think that's kind of what we need to get...at. So you can have an API that gives you a link that you can download the data. So as it was said earlier, you have access to

download the file but you won't be usually downloading the file, you'll be usually wanting to get...using an API to actually get process information, because it takes so long to download the very large file.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

Yup.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yup.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

As an example, that's how it's actually implemented in FHIR genomics now is that there's a link so if you want to you can get the raw data and you can log in and get that information and it's a link to where you download it, but you don't usually use that link, unless you want to get the whole raw data.

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

Yeah Gil has hit it on the head, we really don't need to solve this problem. We just say...

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

(Indiscernible)

Dixie Baker, MS, PhD – Senior Partner – Martin, Blanck & Associates

...we just say we think they should have access to their whole genome.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Yup, I think that's right. So, any other discussion about this last aspect before we move on? Okay, so for me, I think this has been a very rich discussion today and I tried to do some recaps at every stage; I'm not sure I'm up to trying to recap the recaps. So I hope that everybody is comfortable with the summaries that we've had at each phase of the conversation today and Michelle, I think if there's no other items from your perspective, do we have public comment or questions at this point?

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

Yeah, let's open up for public comment.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Okay.

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

Lonnie, can you open the lines?

Public Comment

Lonnie Moore – Virtual Meetings Specialist – 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 telephone and would like to make a public comment, please press *1 at this time. Thank you.

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

So while we wait for public comment we'll take all the feedback we received today and Andy and Leslie will present at the Joint Committee meeting on April 19. They'll share the draft recommendations discussed today and then we'll come back, refine and hopefully present final recommendations in May. And, it looks like we have no public comment at this time.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

All right; I can't say that I'm disappointed, although I love public comment sometimes, sometimes. Don't want to get myself into trouble, but thank you very...everybody very much for the rich discussion today. I learned a lot actually, I think it was a good meeting and I hope you did too. Leslie and I will do our very best to represent the conversations that we've had and we will bring back I'm sure some additional commentary from the combined committees.

I believe Leslie's going to be there in person, because it is a...she and I are both members of the Standards Committee. I will be outside the country but phoning in, so she'll be doing the lion's share of the actual presentation, I suspect. But we'll both be involved and we'll get back to you at our very next meeting. And I hope you have a good day, we'll give you back 15 minutes of your time. Thank you very much to everyone.

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

Thank you everyone and thank you Andy, have a great day.

Gil Alterovitz, PhD – Faculty, Center for Biomedical Informatics – Harvard Medical School; SMART/FHIR Genomics Lead

Thank you.

Andrew M. Wiesenthal, MD, SM – Director, Health Care Practice – Deloitte Consulting, LLP; International Health Terminology Standards Development (SNOMED)

Bye, bye.

Steven Keating – Patient Advocate/Consumer – Doctoral Candidate, Mechanical Engineering, MIT Media Labs

Thanks.