



**HIT Standards Committee  
Precision Medicine Task Force  
Final Transcript  
September 18, 2015**

**Presentation**

**Michelle Consolazio, MPH – FACA Lead/Policy Analyst – 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. Jon White?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Here.

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

Hi, Jon. Leslie Kelly Hall?

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Here.

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

Hi, Leslie. 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**

Hi, Andy. Andrey Ostrovsky?

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

Here, thanks.

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

Hi, Andrey. Betsy Humphreys?

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Here.

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

Hi, Betsy. 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? 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. James 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, James. Josh Denny?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Here.

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

Hi, Josh. Lisa Gallagher?

**Lisa Gallagher, BSEE, CISM, CPHIMS – Vice President, Technology Solutions – Healthcare Information & Management Systems Society**

Here.

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

Hi, Lisa. Mary Barton? And Mitra Rocca?

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

I'm here.

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

Hi, Mitra.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Hi, Michelle.

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

And from ONC do we have Maya and Mazen on the line?

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation - Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

Yes, I'm here.

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

Hi, Maya.

**Mazen Yacoub, MBA – Healthcare Management Consultant**

Hi, yes, I'm here.

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

Hi, Mazen.

**Mazen Yacoub, MBA – Healthcare Management Consultant**

Hi.

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

Okay, I'll turn it over to you Jon.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Thank you so much, everybody welcome, thank you for your time and attention today and every day. This is our last meeting before next week's Standards Committee meeting. So, it's been quite a sprint, really grateful for everybody's amazing effort and attention to this like I said.

We've got a reasonably fast paced schedule for today. We've also got some amazing guests with us to share some late breaking activities. So, here's our agenda. We're going to go briefly through the premature...as mentioned.

Yesterday was the release of a really truly great piece of work and I say that as somebody who has been a fed for 11 years and seen a lot of reports like this but this ranks up there with the greats, NIH's Advisory Committee to the Director reviewed and approved and Dr. Collins accepted the recommendations for the creation of the Precision Medicine Cohort. Kathy Hudson, the Deputy Director of NIH is here with us and will share some of those recommendations with you and we'll have some discussion about it.

Then we're going to hear an update from the HL7 Genomics Workgroup and then we're going to move to review and hopefully finalize recommendations, Maya Uppaluru will help guide us through that discussion. And then we'll talk about potential next steps for our group. So, that is the agenda for the day. Next slide, please.

Okay, here's our membership, again, thank you everybody this is a really talented group, every time I look at this I'm like, holy crap I can't believe I get to work with these people, so, thank you everybody for being on here. Next slide.

There is the mission statement for the initiative, just, you know, it's helpful to refresh yourself and be like "oh, wait that's our north star." To enable a new era of medicine through research, technology and policies that empower patients, researchers and providers to work together towards development of individualized treatments. Next slide.

And this is our charge, I'm not going to read it back to you I think I've kind of bludgeoned you over the head enough with it, but, in case we get to the point where we're kind of, you know, on the fence about some of the recommendations that we're going to discuss next week, you know, it may be helpful to refer back to this. Next slide.

And there is the work plan galloping down the plains we're almost at the...in the last stretch of things, here we are in the next to last cell of this. So, all right, next slide.

All right, NIH ACD update. So, again, just briefly, yesterday there was a capstone presentation of months of, and really in some ways years, of really amazing effort and collaboration led by our colleagues at the National Institutes for Health and with us, as I said on the phone, I have Kathy Hudson and thank you Kathy very much for taking time out of your busy schedule to share the updates from this. It was a great call yesterday and would love for you to lay it out for the folks that we've got here on the phone. So, the floor is yours Kathy.

**Kathy Hudson, PhD – Deputy Director for Science, Outreach and Policy – National Institutes of Health**

Okay and I'm also in a remote location so I'm not connected into the webcast so I don't have the materials so I'm going to sort of just wing it here a little bit. And Jon, what do you want me to do? Do you want me to cover the recommendations or do just a high-level? What would you like me to do?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

You know, well, great, no I appreciate...so why don't we do it this way, Kathy if you want to just kind of give an opening kind of, you know, framing for...

**Kathy Hudson, PhD – Deputy Director for Science, Outreach and Policy – National Institutes of Health**  
Okay.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

The report and the recommendations. Josh Denny I know you're on the phone, would you mind being Kathy's partner in crime and kind of going through the slides? Do you have access to those?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

I do and I'd be more than happy to.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, thank you.

**Kathy Hudson, PhD – Deputy Director for Science, Outreach and Policy – National Institutes of Health**

So, let me sort of kick it off and then turn it over to Josh and Josh is a member of the working group. So, we did deliver a report to the Advisory Committee to the Director about a week ago for them to review and consider and then we met in an open public meeting yesterday afternoon for a couple of hours and presented the recommendations to the Advisory Committee to the Director and they endorsed and embraced the report, had some really glowing things to say about the recommendations and then they endorsed the report and Francis accepted that.

So, we are now in a transition mode from sort of the design phase to the implementation phase. Francis yesterday announced that he is going to be searching for a Precision Medicine Cohort Program Director and as was recommended in the report he wants this person to be a person of considerable scientific seriousness and somebody who will be able to have the authority and responsibility to get this pretty ambitious program off to the races.

We talked some too about the need for speed here because I think it won't be acceptable to the president or really to any of us if we move along at a leisurely pace and instead we're going to try to do things in some new and creative ways in order to get this launched.

So, we're searching for this new leader but in the interim Francis named Josie Briggs to be the Interim PMI Cohort Program Director. Josie has worked a lot with PCORnet, she has worked with the collaboratory, she worked with me at the National Center for Advancing Translational Sciences when it was first formed and she oversaw the clinical and translational science awards. So she has extensive experience in large research studies and is a great...is well respected across the NIH and sits in a great position to be able to move this very transient NIH process forward and in an inclusive way. So, that's sort of the high-level stuff and Josh since I can't see the slides can you walk us through?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

I'd be more than happy to. Great, great introduction and overview. If you want to go to the next slide. So, actually would you mind going to the next slide first and then we'll come back to seven. Let's go to eight first. So, one of the principles...and Kathy just for reference these slides are different than the ones we presented yesterday as we talk through them.

So, one of the big principles was we wanted everyone in the United States to be able to volunteer and become part of this cohort. So, based on that we came up with two primary methods to recruit or two methods to recruit individuals into the cohort by which participants could become part of PMI and they're listed here.

The first, and I shouldn't really say first, they're both just two parallel tracks here, but the first one listed here is using healthcare provider organizations, so that would be organizations, you know, these large healthcare systems out there many of which already have existing biobanks and have informed how we go about doing this and how rapidly we think we could help participants enroll. These healthcare provider organizations would have a longitudinal record of care; they would include accident and medical centers.

We wanted to enable a diverse United States population to enroll in terms of geography, in terms of socioeconomic status, in terms of ethnic background and so one of the ones who are in target were the federally qualified health centers as well as other healthcare systems and academic medical centers.

Everyone, regardless of whether these institutions may have ongoing research efforts that may overlap, everyone would be consenting into the PMI cohort primarily and that would be their new relationship and these HPOs, Healthcare Provider Organizations, would contribute data into PMI on a periodic basis some of which would be centralized which we'll talk about in the next slide.

And then the other method to accrue individuals would be anyone who wants to raise their hand. So, these participants would be direct volunteers we call them and they would basically be anyone living in the US that could see, potentially see a US healthcare provider and they would provide a certain amount of coordinator that would really be overlapping between both people from healthcare provider organizations as well as the direct volunteers.

They must...all individuals that would be volunteering for the cohort, regardless of how they come into the system, would be re-contactable provide a bio-specimen and agree to send or share any electronic health record data that they have or their healthcare claims data.

So, let's go back to slide seven now. So, building on that foundation these are...we talked a lot about how we would organize the data coming into PMI from these diverse data sources and we came up and settled on a hybrid model for centralized and federated data.

So, we wanted to preserve the ability to both do rapid analyses of data and make it really easy for researchers to access data from this huge national resource but we also wanted to preserve the ability to get at the deep dense data that exists within our electronic health record systems to answer detailed questions some of which may require re-contact of the individuals to ask them specific questions not to mention the potentiality to do targeted clinical trials and things like that.

So, the centralized model at the coordinating center would have an analysis ready core dataset that is curated using some common data models and would be a...really that coordinating center would serve as a hub for both data and bio-specimens that would all be centralized. And then we'd have this hybrid structure by which we could access data at a federated level at healthcare provider organizations.

Now a key element of this is how you get data from the participant direct volunteers. And then the...we expect this common core dataset would initially start with electronic health record data, claims data from insurance companies and others, surveys, a baseline health exam for everyone, mobile health technology and other sensor data, it would start with prevalent smartphone use, which is in 2/3 of the population and would also include bio-specimens namely probably blood to begin with for genomic and other types of analyses.

And let's go...we can move onto I guess slide nine now. So we wanted to make sure that there are proper safeguards around data access and enrolled-based data access for researchers. There would be a...to guide this there would be a central IRB across all for PMI.

We have the principle of using de-identified data wherever possible, especially in analysis, but before that many research studies don't actually need to know who the participant is but some of course do and when you need to know who the participant is there of course is that ability to re-contact the individual and touch base with them.

We wanted to discourage data from being copied outside of a secure computing environment and so we wanted to provide centralized access and sort of an enclave model that would have security protections around it but support a wide variety of computational uses.

We wanted...we felt it was important to clearly articulate breach responses and notification plans and make sure that participants were aware of the fact that we will do the best job we can to protect their data but it is possible that things could happen and what would happen in that case.

And then we noted several privacy gaps that are detailed there, the Freedom of Information Act with regard to genomic data, the possibility for unauthorized re-identification and when to specifically prohibit researchers from doing such activities and have teeth in the process for that. And we talked about requiring data users to secure certificates of confidentiality. Move on, next slide.

In this core dataset, I've talked a little bit about this before, but I would have a standardized set of self-report measures that would be assessed directly from the patients, this would be based a little bit on...and articulate with those who have gone before us such as the UK Biobank and Million Veteran's Program, there would be a baseline health exam at enrollment and we're still working out how we would do that for the direct volunteers but for the folks coming from healthcare provider organizations they would establish processes to develop a baseline exam and this should be standardized across both routes.

And then the structured clinical data we want are listed there. So, at initiation we'd want to be able to have all billing codes with dates, we'd want to have high value clinical value labs that get structured and there is some existing formats and folks that have done that.

We want to have measures and reference ranges along with the labs, we'd want to have medication data, as much medication data as we can get and annotate that with as much signature information as we can essentially get over time. Vitals, we want to have knowledge of all their encounters and if it is a healthcare plan we want to know when they were enrolled and when they were no longer enrolled, what kind of coverage they have.

As we get bio-specimens we want to of course know metadata around that, and then mobile health data is probably one of the least standardized datasets out there right now. It's often possible to get these in structured formats but the structured formats are Venn diagrams with very little overlap in many cases at this point but we think PMI can catalyze some standardization in this realm.

From direct volunteers it's very important that we have and develop standards that will allow us to transport data from electronic health records and insurance companies and others into PMI and this is probably one of the really, really key areas for development in standards going forward I think for the success of PMI will be extensions to Blue Button technology and view, download, transmit technologies that would really be whole record enabling and sending of these data, and hopefully to even project to a link that would move forward. Next slide.

So, I guess that's it. We have termed that sort of linkage forward to be saying, we've used the term "sync for science" and you've heard us talk a little bit about that before, this idea that we could have a continuing update that the participant wouldn't necessarily need to remember to upload and re-upload their data all the time when they accrued new healthcare information. So, that's a brief overview. Kathy do you have anything else or Jon that you wanted to add?

**Kathy Hudson, PhD – Deputy Director for Science, Outreach and Policy – National Institutes of Health**

That was great, that was great Josh.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Awesome, yeah, no I...the only two things I'd have to add is, you know, folks what you've gotten is, you know, all, you know, literally directly from the horse's mouth, a really good synopsis of, you know, salient points. Overall it's a really well done report and I recommend it for your weekend reading if you get a chance it's publically available and you can find it all over Twitter and on the NIH Precision Medicine page.

So, with that...and the last thing I would add is that, you know, if this isn't enough for you next Tuesday we've got a Twitter chat going on, Kathy will be on it and Dr. Collins will be on it, and BJ Patel will be on it, and Josie and for some reason me. So, we'd love for you to join us on that as well. Okay, so with that let me stop and ask if there are any questions from the Task Force or comments that you have about what you've heard?

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Jon, this is Les and I have a couple of comments. I think this is really amazing because now we have an actual use case to work for and constraints, and opportunities that have been defined for this group so I think we can look at our strawman of recommendations with this now use case in mind. So, that's some really good direction for us.

I did have a question on the previous slide on the framework for privacy and security and I am encouraged by your recommendations to use de-identified data whenever possible or feasible and I wondered if the group talked about perhaps having the bias be for data to be de-identified even when there is another data source that would help link back to the identity of the patient so that we could have a framework that from the get-go protects that data so that we don't have it directly attached to the patient's identity but there is some sort of next step that has to take place. Did you talk at all about any kind of function or frameworks around you'd handle both de-identified and identified information?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Sure, so, we did talk about that and we thought if we talked about that we could take all the data and have it in a de-identified format including the narrative text data that we would have centrally stored and then separate the identifiers out and we even talked about, you know, you could even sort of physically electronically, database-wise, separate out the identifiers from the core data in the process and that would include of course, you know, the identified data and even when you get access to identified data, you know, it could be based on the kinds of identities that you need to know and there are many layers that you could think about sort of limit the dataset and the identifiers and that could all be adjudicated at the resource access level.

So, we did talk a lot about that, we didn't go into tremendous detail about all those potential options in the report but we affirmed kind of there are possibilities of kind of having layered access to identifiers including removing identifiers in automated fashion as possible from data.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Thank you that's great to know. Great guidance for us.

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

Hi, this is Eric Rose; I had a couple of quick questions. Thanks for the presentation it was...you brought a lot of clarity in a very short amount of time. So, my two questions are what's the incentive other than altruism for members of the public to participate in a cohort and the second question is, I just want to clarify, by design the data store for the cohort will include personally identifiable information like names and addresses is that correct?

**Kathy Hudson, PhD – Deputy Director for Science, Outreach and Policy – National Institutes of Health**

Yeah, so this is Kathy...

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

It will...

**Kathy Hudson, PhD – Deputy Director for Science, Outreach and Policy – National Institutes of Health**

Josh, do you want me to take it?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Go ahead, Kathy.

**Kathy Hudson, PhD – Deputy Director for Science, Outreach and Policy – National Institutes of Health**

Okay, so, yes, there will be identifiable information that will be retained and of course that's essential because this is a longitudinal study and we'll need to be able to go back to people.

In terms of the incentives we had an opportunity during the planning process to work with the foundation for the NIH to do a survey of the public asking people about their general views towards a cohort study of this sort and also what kinds of features would make participation in a cohort attractive to them and overwhelmingly what we heard back was that getting information about themselves back was the number one incentive. And then there is a deep thread of altruism that runs through the survey responses and so we think that this will also draw people to participate.

So, you know, it's an interesting question. When we open enrollment, particularly for the direct volunteers that Josh described, I think it is hard to project how many people will in fact raise their hand and want to participate in this big audacious national effort. We have not talked about compensation per se as a part of the cohort believing that we'd be able to secure ample participation in the absence of that.

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

Thank you very much that helps.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

All right, other Task Force members with questions or comments?

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

Hi, this is Christina, so congratulations to Kathy and others I think this is great. I had a question about the re-contact and I understand that some re-contact or the participants need to agree to at least some level of re-contact as a condition of participation. Can you describe a little bit more about what's envisioned with that and also will there be certain types of re-contact for which the individual will have choices?

**Kathy Hudson, PhD – Deputy Director for Science, Outreach and Policy – National Institutes of Health**

Yeah, so let me start and then ask Josh to chime in as well. So, we laid out in quite a bit of detail the kind of information that we would be seeking at enrollment from all of the participants and that's laid out in a nice table in the report. And then...but we were less clear in the specifications for additional information over time although we put forward a whole array of specimen types and information types that we might want to collect over time.

I think that one of the critical features of this cohort is that it's going to have to be adaptable and flexible, and evolve rapidly with new scientific opportunities and new technologies, and so the specifics of what kind of information and measurements we would want over time has not yet been detailed with great specificity.

That said, I think there will be studies and analyses, and specimen collections that will be core to the Precision Medicine Initiative and all cohort participants and then there will likely be some studies that are launched within a sub-part of the cohort either to try something out to see whether or not it would be worth using in the entire cohort or because of the direct applicability only to a subset of people.

And then there is also going to be an opportunity for people doing sort of related but not directly PMI studies with PMI participants and so we would want to be able to go back to people and invite them to participate in an associated research study and that might be a clinical trial, it might be something else.

And then we envision that there will be the ability to contact people in an easy, non-intrusive and inexpensive way and so the idea of being able to interact with people through their mobile devices is of course particularly appealing and with the broad uptake of smartphones that seems like a reasonable approach. Josh, what did I miss in that overview?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

You know I think that's great, I think you covered just about every part of it. I think the key thing to say is, you know, this is a longitudinal course that will last a long time and so there will be lots of things that come out of it that participants may or may not, you know, participate in based on a whole bunch of things which include their preferences but also just their course through health and disease, and what studies they may become part of based on that. So, yeah, so there will be a lot of personal driven direction in what they participate in and what they end up sharing over time.

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

All right, thanks.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, it's Jon, so excellent discussion. In the interest of time I am going to close comments and questions, again, I want to tip my virtual hat to Josh and Kathy, and colleagues tremendous process, tremendous product and I really think that precision medicine is on its way, this really advances things along. So, thank you so much for the time and attention, and frankly participation that you've been willing to give us of your valuable time. So, cheers.

**Kathy Hudson, PhD – Deputy Director for Science, Outreach and Policy – National Institutes of Health**

Thanks, Jon.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Yes, you bet. So, next slide.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Thank you.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, now we're going to move to an update from the HL7 Clinical Genomics Workgroup Gil, Mollie and Amnon, and are you folks on?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women's Cancer Center & Partners Healthcare**

Yes, Mollie is here.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Hi, Mollie. Gil or Amnon are you there? All right, Mollie, I guess the floor is yours. I hope that's okay with you I didn't know if you needed your colleagues with you or not?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women's Cancer Center & Partners Healthcare**

Is there an opportunity to share slides or should I just speak to them?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

So we have a slide deck I'm not sure if you slides got included.

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

So, actually, yeah, sorry, this is Maya, Mollie we have just a couple very brief like here are the people that are on the workgroup slides. I didn't realize that you had separate slides though. So, I don't know. Michelle is there a way to send them out really quick if we were to do that or...

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women's Cancer Center & Partners Healthcare**

Or I could speak to them and we could...

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

It could be follow-up.

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

Yes, I think that would be better.

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

Okay, we can do that.

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

Thank you.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

Okay, so my name is Mollie Ullman-Cullere and I’m a Co-Chair of HL7 Clinical Genomics Workgroup, also serve as an HL7 Liaison to the College of American Pathologists Biomarker Reporting Committee, and in the daytime I’m a Senior Biomedical Informaticist at Dana-Farber Brigham and Women’s Cancer Center and Partners Healthcare.

So, a large portion of my time is considering several major questions that I think would be very relevant to you folks and that’s, you know, how do we unify efforts, integrate into clinical systems, extend healthcare IT standards for genetics, support interoperability and diverse solutions, and achieve testing platform independent reporting.

So, in unifying efforts I was involved...I had the wonderful opportunity to be involved in the Department of Health and Human Services and ONC personalized healthcare use case in 2008 and really got to experience how pulling together a diverse group of people and key stakeholders led to the creation of a roadmap and a deep understanding and commitment by these individuals to further personalize healthcare. This has since gotten out of date.

In the absence of a framework at the Department of Health and Human Services and ONC level, HL7 has tried to replicate this as best we could in that we’ve created a domain analysis model for clinical genomics and this begins to address the challenges involved with the diverse work flows, for instance, germline testing versus somatic testing, the challenges with managing specimens, the relevant metadata that other organizations within HL7 or workgroups within HL7 will want to consider as they build out their models, for instance a specimen model. And this has passed ballot and will be published this quarter.

For integrating into clinical systems, again, it’s a domain analysis model that really helps drive the important key minimal core datasets and elements that are going to want to be captured because we have a great deal of complexity, we have laboratory information systems that already exist, specimen management systems, ordering systems, electronic medical records and discovery research warehouses already exist, and we have to have a way so that we’re communicating and educating the community as important information that needs to be captured to support the complexity of data and enabling them in a stepwise fashion to do that as might be sensible to efficiently implement it in their systems.

For instance, if we have a messaging standard that uses LOINC templates with LOINC codes and specifies, you know, use an HGNC gene symbol, use and NCBI ensemble reference sequence that implementers can choose to get their laboratory databases updated, start to use this information in their narrative reports and start to transmit this information into discovery systems and enable the electronic medical records that seeing these maturing systems that need to transmit this data and utilize this data then the electronic health record systems can actually start to build out infrastructure to retain this structured data.

For extending healthcare IT standards for genetics we found leveraging LOINC codes to be incredibly valuable. We’ve worked with Clem McDonald at the Lister Hill Center at the National Library of Medicine and Stan Huff at Intermountain Healthcare, and we’ve extended LOINC in a fashion so that we have developed LOINC panels which serve as templates almost like an address template that you would fill in your first name and your last name and address line one, and your apartment number and city, street...city, state and zip code. And we have those templates for genetics.

And what the codes...what the LOINC codes do is it gives healthcare IT systems a recognizable handle to except and extend into the genetic standards. So, for instance, the LOINC code for gene identifier expects, and it's required, that an HGNC official gene symbol and gene identifier be associated with that LOINC code. We also have LOINC codes for the reference sequences that will then link out to NCBI's ref seq or ensembles sequences, also to HGVS nomenclature. So, the LOINC codes have been incredibly helpful.

To support interoperability and diverse solutions the LOINC panels provide a template. So, these LOINC panels and codes we don't care if they're in an HL7 2.5.1 message in OBR and OBX segments, we don't care if it's stuffed in a JSON string or XML in a 2.5.1 Z segment. We don't care if it's in a FHIR profile or if it's in a CDC or CDA document. The point is that because we've taken this approach you could put them in any type of format and the receiving system should be able to parse through and know how to handle these.

Then we also have identified the need to achieve testing platform independent reporting and this was identified through work with the cancer registrars who actually review the electronic medical record results for cancer patients and they were complaining that even within the same laboratory the genetic test results were reported in different formats depending on the testing platform. So, gene...kit had one format saying or sequencing and next generation sequencing. So, what we've tried to do in HL7 is to be inclusive within these coding systems to accept and unify these formats.

So, we have a number of resources that are available with the demand analysis model and use cases, various implementation guides, the LOINC codes and panels. We also have these for family history and we have them across a wide variety of messaging standards including support now in FHIR which is an emerging standard.

In conclusion, some of the recommendations I would suggest are to develop a 2016 ONC precision medicine use case, engage stakeholders across the full domain and identify and support long-term genetic references and promote LOINC coding working closely with the Lister Hill Center and also implement platform independent reporting policies. Thank you.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Mollie, it is Jon White, thank you so much for an excellent presentation both succinct and rich. So, if you don't mind I will start off with a quick question. So, just to try to translate what you've just told me or told us, into recommendations that this Task Force ought to bring to the Standards Committee next week, it sounds like that we ought to recommend the use of...you're saying that we ought to recommend the use of LOINC, okay, and that we ought to support other relevant standards development organization's standardization efforts that are underway and make sure that those are accounted for in the Precision Medicine Initiative. Did I...am I repeating that back to you correctly or did I get something wrong?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women's Cancer Center & Partners Healthcare**

Yes, I would also suggest, I'm not...you may have something in the works already, but the personalized medicine use case that was done in 2008 was an excellent way to bring together the community and discuss the complexity of workflows from a healthcare IT perspective.

So, for instance, when you were getting a cancer specimen electronic medical records often have an order that would be in place that would expire within 24 to 48 hours if a specimen wasn't received and with cancer it takes longer than that for the specimen to arrive and be attached.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Gotcha, so an additional recommendation would potentially be start with the 2008 use case and develop it out for, you know, modern day scenario and kind of elaborate on that. Is that right?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women's Cancer Center & Partners Healthcare**

Yes, because cancer is going to permeate throughout the medical record, you know, whether it be drug ordering or...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

There is a bad joke to be made about metastasis there I think, so, but, yeah, no that's a great point. Okay. So, thank you for letting me ask my question. Other folks on the Task Force questions or comments?

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

I also, this is Maya; I just wanted to note that Gil is also on the line now so...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Oh, hey, Gil.

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Hi...

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

So if you have questions for him.

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yes, I was just having an issue with the microphone before so I couldn't respond it was on mute.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Oh, no worries. So, Gil, I appreciate you kind of coming back on. Is...I'm hoping that you had a chance to hear the presentation.

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yes.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Is there anything that you want to add?

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Certainly, yes, so I can talk about things regarding maybe add a few more details on FHIR. There's been...FHIR is the latest of the efforts that...in terms of clinical genomics that HL7 has embarked on and it's gotten just unbelievable traction already with a number of organizations interested in piloting that and so I wanted to kind of mention maybe some of the advantages and disadvantages of FHIR and looking at that.

So, FHIR kind of emerged for a number of reasons one of which was to create simplicity, more simplicity and conciseness to make it easier for developers to develop applications that communicated clinical and now genomic information between the electronic medical record and potentially Apps, and other sources.

And so there was kind of some...had been some concern after HL7 version 3 the RIM and so forth that there is a lot of complexity and then at the same time in some of the version 2.5.1, which had been widely adopted in the clinical realm, had not been as widely adopted in the genomic realm and there are a number of potential reasons for that, but that's kind of what happened and there is agreement about that in general.

And so FHIR, you know, was trying to create a standard that looks at some of the more modern technologies, web-based technologies, RESTful API and so forth to allow and enable more widespread use. Some people might say, you know, it's kind of like maybe creating almost like and enabling the creation of something like an App Store and on the other hand it did not focus on some of the technologies that would enable an App Store and for those I think...and I saw on your recommendation list you have it in there SMART on FHIR is probably the solution for that looking at how do you...what technologies are useful to enable the communication between the EHR and other entities to enable Apps whether it be the authentication and so forth.

So, that's kind of where FHIR is now...those are some advantages of FHIR, some of the challenges and areas that FHIR is now, you know, working on is, you know, we're now working on piloting and taking the standard through and trying it out on different locations and in doing so learning, you know, more about, you know, what kind of things are needed as we develop kind of Apps which are kind of different from how HL7, you know, 2.5.1 had been used in the past where everything was integrated all in one electronic medical record program created by the vendor.

So, just creating a lot of interesting items and I guess one potential, you know, thing that I'd suggest might be a recommendation is to think about, you know, some of the use cases you have and how they could be turned into Apps that might be reusable in some cases and might need or might be customizable for certain locations in other cases and so by creating an App that is substitutable and reusable you can really allow precision medicine to be done in a way that's most suitable for all the different sites and that could potentially use, you know, FHIR underlying and potentially SMART on FHIR for enabling the App space to take place.

So, I think, that's kind of mostly what I wanted to go over and then see if you had any questions.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, fantastic. Task Force members the floor is open to you.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Jon, this is Mitra from FDA, I actually invited the Co-Chairs of the HL7 Clinical Genomics to present to us this came up at our last meeting I think. So, just the background.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, thank you, good background.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

This is Leslie and I have a question about the patient generated health data that would be required to support the cohort and wondered if you also, as part of your work, looked at that?

I heard Mollie mention something about using LOINC for the patient demographic field and I think we're covered today with that and want to use existing standards already named. But wondered if you had looked at any of the work on the HL7 Consolidated CDA patient generated data header and questionnaire structure or what you've done to include the standards for that?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women's Cancer Center & Partners Healthcare**

Gil do you want me to take that?

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yeah, I think she said, Mollie, yeah, so it sounded like a...why don't you go at it first, yeah.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women's Cancer Center & Partners Healthcare**

So, in that the approach we've taken with HL7 is that we focus on the genetic specific content or how specimen information may need to be enhanced for genetics and we rely on the other workgroups to focus in their very specific areas so that we can be interoperable with and work well with anatomic pathology or bridge, or these other workgroup efforts.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Thank you, so your emphasis has really been on what's coming out of the lab into the EHR and then coming out of the EHRs into the researcher?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women's Cancer Center & Partners Healthcare**

Yes and also within the laboratory. So, the elements that need to go into the lab order into the EHR would be relevant, you know, throughout that system because you may need to collect those elements from the order, but, yes.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Thank you.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Other Task Force comments?

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yeah, this is Betsy Humphreys, and I'm going to ask a question and maybe in addition to Mollie Josh might have some insight on this. The work that Mollie and her group have done in conjunction with Clem and others across the spectrum has been really important in terms of getting the results of specifically ordered genetic tests transmitted and incorporated in EHRs and used for other purposes with sufficient specificity so that we can really interpret the tests like the inclusion of reference ranges and so forth so this was very important work when it was done because people were sending around, as I understand it, information about mutations but since they weren't using the same reference range or variation, you know, it was kind of not interpretable or difficult to compare across the thing.

So, in the case of the PMI cohort we're going to have a full genome for every participant but then in the case of the data that's going to be sent forward from their routine healthcare for those that are sharing, you know, in systems and since we're expecting EHR data to come in, I guess we can assume that we will also be getting specific genetic test data that was ordered because of whatever reason for a particular person.

And I'm just wondering, Josh if you can tell me, whether in the eMERGE and the other, you know, cross platforms things that you're familiar with, whether in fact people are picking up genetic testing results and so forth transmitted according to this HL7 standard and whether you see that the HL7 standard for this obviously will be a good thing going forward for collecting EHR data for the PMI cohort?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

That's a great question Betsy, two things, first I want to say that initially in the cohort we will be collecting blood for DNA and cells, and things like that, we won't necessarily have full sequence data on everyone for a while but likely in the early stages we will be doing dense genomic genotyping including pharmacogenomics experience on probably everyone that would be done on the cohort.

Now in terms of the second question which was key in terms of the utilization of the HL7 standard, in eMERGE and also part of a network called IGNITE implementing genomics in practice, which has six sites and really spans probably about 40 institutions, I am not familiar with anyone that actually has clinically implemented HL7 genomic data on kind of a broad scale.

Most of the tests for genomics come back as, you know, PDFs or just sort of narrative text documents unfortunately at this time, and those who have structured it in the EHR typically, at this point, have predated the evolving genomics standards and for that reason have created, including ourselves, their own sort of, you know, "bespoke standards" so to speak.

And so we are...I can tell you we are...we have represented our test results for the most part in the genomic standard and have representation on that group with some of our feedback of what we found. And we'll be using it to transmit results probably within the next maybe...yeah, I would think within the next year we'll be sending genomic test results in the HL7 format to other hospitals but that may...I don't know of any other implementations that are sort of broad scale, but certainly I'm probably not the expert to comment on Gil or...

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yeah, this is Gil, yeah, I'd be happy to mention one example of Jeremy Warner, a colleague actually of Josh and myself, and he has a pilot that he has built that uses...basically it's a precision cancer medicine App and it integrates with the data warehouse of Vanderbilt and looks at a number of the variant...it reads the variant information and compares the individual's variant information for a particular lung cancer and compares it to the population within that database and he uses the FHIR, you know, the FHIR clinical genomics, you know, standard that's being, you know, part of HL7.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**  
It is...

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

So, that's one example but it's just within Vanderbilt.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Yeah, right, so unfortunately the data, you know, doesn't...didn't originally come off in the standards.

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Right.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

So, this is Betsy, this is...

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yeah...

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

I was really glad that Mitra arranged this because I think this was an issue that we were talking about last week exactly sort of where are we in the implementation of the standard, but it does, based on what you were saying, Josh and others, it seems to be that this is a reasonable standard for us to try to point people toward even though it is not...it's one of these emerging standards that it seems that there could be benefit across healthcare in general and in general for the...and particularly because it's been set up to, you know, be agnostic in terms of the specific form of transmission and so forth.

I think that it would make a great deal of sense for us to be, you know, sort of pointing toward this as an emerging standard that we think should be used for...in the future for...or we hope will be used in the future for obtaining genetic test results for PMI participants. Does that make sense to you or is that not a reasonable recommendation?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Yes, I think so, I think, you know, use of a standard always helps its evolution too. So, as we get more use cases and point towards that I think it's a great one for...and I guess it's maybe the only one too right at this point for being standardized and being a transmission protocol.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

I have a question for Andy. Andy is there impact when...when the data is coming in, where using SNOMED and other types of data around this and now we have a LOINC rich dataset, is that an unintentional operational computation inside the EHR and so when we have that kind of separate vocabularies coming in?

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

So, this is Andy Wiesenthal, I think the Andy you're referring to is me?

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Yes.

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

I apologize because I...but I only caught about half of the words you said. I think what you were asking was something about if a patient is related to SNOMED and LOINC but I don't really...I didn't get the gist of the question.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

I think I did, Andy, this is Betsy, my...I believe the right answer to this question is that we are talking about, in essence, lab test results here, genetic tests and I think that specific test results, lab test results, the general plan here is for those to be specified in LOINC and that is standard and then for...through the cooperation between the Regenstrief Institute and the IHTSDO that is responsible for SNOMED for there to be a principle relationship between the very specific representation of the test and the test result and SNOMED at a higher level.

So, I don't...just the way lab test results are currently being...other types of lab test results are currently within health systems in the United States being represented increasingly in LOINC because that's the standard for it. I think that having genetic test results also specified in the same way is just reasonable.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

That's exactly what I was asking, thank you, Betsy.

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

Thanks, Betsy.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

This is Mitra I have a question for Mollie and Gil. So you developed HL7 CDA release 2 genetic testing reports are there any plans to include that in Consolidated CDA?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

So, working with the authors of the Consolidated CDA the guidance we received was because our vocabulary is LOINC coded and encompassed within the larger healthcare IT HL7 vocabulary that this is fully portable to a CCD.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Thank you.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

The only thing we don’t have is an implementation guide for CCD.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

I see, okay, thank you.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Thank you, so...

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

This...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Oh, sorry, go ahead.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

This is Les, just one more question, how does HPO fit into your view?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

Could you...

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Mollie, did you have something to say about that otherwise I can talk about it.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

I...

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yeah, go ahead, go ahead. Yeah, Mollie, go ahead you have HPO.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

Was it the human phenotype ontology or there is also...

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Yes.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

An HBO. Is it the HPO?

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Yes, “p” as in “Paul.”

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

Okay, so in that because we’re working in the clinical space we actually have needed to link to SNOMED or utilize SNOMED. That said, it is a pleasure working with LOINC, it has been a real challenge working with SNOMED. So, I think that’s for, you know, ONC to take a look at to see if they should extend to other phenotype ontologies for genetics.

The challenge if you don’t get an official blessing on it that you can transmit it but the medical record cannot read it and that’s why LOINC has been so key is because it has given us an official hook into some of these very gene specific ontologies like the gene symbols.

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

So, this is Andy and I would...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

This is...

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

Can I ask a question? Was it the challenge working with SNOMED structure with IHTSDO the organization? Which is the challenge?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

The process, the organization.

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

All right...

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

I also work in cancer and I have to say pathologists have, you know, even stated frustration in using SNOMED for coding anatomic pathology.

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

Well, they’re the ones who built it.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Well, so, it’s Jon, in the interest of not bashing SNOMED I think we’ll look to try to make everything work together. I’d also amend that when you said it would be ONC to take a look at that it would be...

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

NLM.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

ONC coordination with...yes with its partner, exactly, Betsy, so Betsy and her colleagues. So, appreciate that. I don’t want to prematurely cut off discussion; however, I do want to make sure that we get to discussing our recommendations. So, any important questions remaining from the Task Force?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

Could I add one comment just so I don’t bash SNOMED, these had a lot of other things that were a higher priority with Meaningful Use. So, we have not been on their priority chart.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Oh, but now we have PMI, you’re elevated up. I’ll send you some of the background I sent other members of the committee, Mollie this is Betsy, about what we’re trying to do in terms of HPO and connections to SNOMED now.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

Excellent.

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yeah, thank you, this is Gil here, again.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, going once, going twice? All right, silence is...Mollie and Gil thank you so much and Mitra thank you for arranging that.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Okay, you’re welcome.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

That was an extremely helpful update. So, okay, so before we get to the final segment here are there any other Task Force members that were able to join us late that just wanted to announce themselves?

**Claudia Williams, MS – Senior Health & Health IT Advisor – Office of Science & Technology Policy – White House**

Claudia Williams here.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Oh, hey, Claudia.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Hi. I guess I'm an invited guest but I'm here.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Yeah, let's use the right terminology for God's sake in this group, right? Oh, good, okay, anybody else? Okay. All right, so with that let us then kind of say again to the policy here, you know, sometimes you kind of glide in for a nice landing and in this case I think we're coming in high, which is fine, so with this let me turn to Maya Uppaluru, she and Mazen have done a really nice job of kind of trying to organize recommendations for us to consider.

Maya, would you mind kind of walking us through what we've got and I would ask folks that I know we're scheduled to go to 11:30 we may want to consider going just a little bit beyond if there is significant discussion on any of these given that there's a Standards Committee meeting next week. So, with that let me turn it over to you Maya.

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

Sure, thanks, Jon. So, I can take you through the way that we've set everything up but then I might turn it back to you and Leslie just to go over the content. So, if you want to go to the next slide.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Absolutely.

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

So, here, we've tried to kind of capture some of the things that have come out of the discussions thus far. As we demonstrated with the Excel sheet last time, which I know was really difficult for people to see, we've now converted those into three slides, four slides actually, as part of this deck. So, the first is readily applicable standards and we have kind of color coded that as green it's a little easier to say.

The second is promising standards for PMI and those are going to be yellow. So, those that may require additional effort, ONC investment, private sector investment, etcetera, and we can go into more detail about what kinds of accelerators are needed for each of these buckets.

And then the third bucket, the standards gaps and those are color coded in red so areas where we need considerable more work, considerably more work.

And then the last bucket is other accelerators. So, what opportunities can we identify in terms of ONC investment, other opportunities to advance or improve these standards in the aforementioned three categories? Next slide.

So, again, I might turn it over to Jon and Leslie here to go through each of these, but we did our best to kind of glean from the conversations that we heard what should be in this green bucket. So, we heard last time the standards that we currently reference in certification and we put in the HL7 family health history pedigree work here with a note that we did hear some conversations that there were more opportunities to further develop this and again, none of this is set in stone, if you all on the phone strongly feel like something in here belongs in the yellow bucket or vice versa this is just a jumping off point to start the discussion.

OpenID Connect and OAuth, sometimes we put that in the emerging standards or what I guess here would be the yellow bucket, we put them here, if we need to reclassify that...they are obviously widely used throughout industry but, you know, we've heard that they need more testing and piloting in this specific context so they could really go in either depending on how you guys feel. So, I don't know if we want to discuss this first slide? Jon and Leslie do you have any additional comments before moving on?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Well, actually, so it's Jon, so if you don't mind just run through the green, yellow, red and then the accelerators.

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

Sure.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

And by the way tip of the hat to Leslie for the accelerators that was not my original thought...

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

Yeah.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

But that's a great idea.

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

Yes.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

So, just run through them and then we can come back to the green slide and then we'll tee up any discussion, you know, by section.

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

Okay, sounds great. Next slide, please. So here we put FHIR, we put the HPO work, computable patient consent and then the IOM genomics roundtable and we should probably put this on a separate line but the Genetic Alliance work. So, again, things that are emerging, promising, that require further testing and piloting in the field. Next slide.

And then here we put things that we heard definitely need more work so for example the race and ethnicity standards from OMB, and then microbiome standards came up on one of the calls, and then there are two kind of action items here for ONC that I would raise the question as to whether these should be in the accelerator bucket which is going to be the next slide, but again, I'll leave that to you. So, if you want to move to the next, yeah.

So, I kind of put in this first one, I would raise this question to the group, what are some additional areas where ONC can invest in pilots for example of FHIR or around a particular use case, so we heard Mollie talk about the potential to develop a 2016 PMI use case and do more work around there.

And then we put some of the genetics and the dbSNP and ClinVar things in here. So, again, just a jumping off point to start discussions and there may be other things that we didn't hear on the previous calls that need to go in here. So, yeah, with that maybe we can go back to the original green slide and get a little more in depth.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Yes that would be perfect. Yeah, the only framing comment that I guess I would add here folks is that, you know, what...over the past two months what I've pretty clearly heard from you all is that, look there's really good promising stuff here, there's more work to be done after this.

So, in terms of recommendations that we think we ought to advance to the full committee for their consideration next week I would say that, you know, if we're in doubt about anything or if we're not quite sure, if we're not like kind of, you know, really kind of there with it, you know, now is the time to say so and we could say, look, you know, we'll kind of put this, you know, recognizing that there is not consensus within the Task Force that this is stuff we can put on hold for later.

That said, you've also heard, I mean today from Kathy and Josh, that, you know, trains rolling so to the extent that we think that there's stuff that really ought to be used, you know, now is the time to say so and so it's an exciting opportunity, right, to leverage the work that we did. So, that's my framing. Leslie, anything else that you want to say before we get into the specifics?

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

No, I think you've covered it, thanks, Jon.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Awesome, okay. So, with that for the readily available or applicable standards, this is the green slide, Task Force members any comments or thoughts about these specifically?

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

This is Betsy, I think under this first one that we should get a couple of people to put their heads together and actually list them because people who have been immersed in Meaningful Use and certification, and whatever, might be able to generate the list of the standards that we're talking about but I think other people who are looking at this may not know what we're talking about.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, that's a fair one.

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

This is Eric, for the third row there I think that the...there are two questions, the big question of course is should family health history be expressed as a pre-coordinated, a code to represent the pre-coordinated concept, you know, family history of Huntington's disease or should it be post coordinated with a code representing Huntington's disease and some metadata representing family history of.

And this group of course shouldn't make that recommendation in isolation. There are...I know there is a huge amount of work already going on for instance in the Structured Documents Workgroup I think it's called in HL7 and so forth and so, you know, the advantage of course of a post coordinated approach is you get all of the disease concepts in SNOMED to pick from which is a much larger set than the one sort of pre-coordinated with family history.

The second thing is considering whether SNOMED should be used to represent the familial relationship of the family member in question to the patient, the maternal grandfather that sort of thing.

**Claudia Williams, MS – Senior Health & Health IT Advisor – Office of Science & Technology Policy – White House**

This is...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

So that could...oh, just real quick, so Eric that's good. Does it...I can't tell, does it sound like there's potentially two separate recommendations for the first issue in terms of the pre or post? The first recommendation being that you ought to use the standard but the second in terms of how it's implemented that we ought to be testing the pre or post methods.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

Could I ask a clarifying question? This is Mollie.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Sure.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

There is a historic form of capturing family health history on the problem list which uses SNOMED but we also have the HL7 family history and pedigree model which allows you to capture the familial disease or risk within a larger model and it doesn’t have the pre-coordination because it’s already captured within a familial relationship within the model itself. And so it’s a little confusing.

When I read this I thought SNOMED it was coming up with a value set of familial conditions that can be expressed in SNOMED that would have sort of as we have our Kaiser, VA value set for the problem list we would have a similar value set for family history so that we could have more uniform and accurate computability and risk algorithms.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

I agree with Mollie that what we’ve got specified here is a little under specified, but the other question I need to ask, Jon, you’re going to know this, I think, are we going to submit these recommendations before you publish the final EHR certification rule? I mean the 2015 rule?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Well, I can’t comment on when we’re going to publish the final certification rule. What I will say is that we are planning to submit these recommendations for discussion and consideration, okay, by the Standards Committee, which is going to be next week on Tuesday.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yeah.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Now that doesn’t mean that they get accepted and finalized, and forwarded to the Secretary on Tuesday.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yeah.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

But, you know, these things are happening in, you know, relatively close coordination. So, that’s definitely a factor to kind of keep in mind. So, that’s a great question.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

I mean, not to...I think it is obviously public knowledge that there were recommendations...there was a discussion in the Notice of Proposed Rulemaking there was some discussion of how family history might or might not be treated in terms of certification so.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Yes and I think the other appropriate thing to say is that, you know, at an internal staff level, you know, as we were doing our best to coordinate with the NIH Advisory Committee to the Director recommendations we're also doing our best to try to coordinate with those other large moving objects.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yeah.

**Claudia Williams, MS – Senior Health & Health IT Advisor – Office of Science & Technology Policy – White House**

This is Claudia and I really like this list. I have a suggestion for another layer before we finalize both this and the next, all three I guess, and I unfortunately can't stay past 11:30, I think we made a lot of progress last call in narrowing the scope of what we want to look at to sort of two major areas that I can remember, one being, how can EHRs help populate the Precision Medicine Cohort itself?

And the second was, how can EHRs be a more robust place where clinicians bring in genomic data and make decisions for patients?

So, that can help us also prioritize which things are things we need to work on and which aren't and so I think all the things on this page would relate to one of those domains.

When you get to the second page, and I know we're not there yet, but when you get to computable patient consent I'm actually not certain that's an area that would need to be worked on directly, unless I'm not thinking about it right, because for the cohort itself the consent is likely to happen outside the EHR. It may be that we need that for the clinical care piece but we'd need to talk that through.

So, I just would like us to go through another layer of prioritization that takes these domains, which are really thoughtful, and layers on is this a high priority for either one of those kind of use cases that we might want to move forward on. So, I'll...

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

It...

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

I would second that entirely. I think that, you know, like the consent for instance will be something that is handled within PMI separately and similarly like, you know, you could also say, like microbiome data standards are not likely to hit the EHR any time soon. I know that's probably an obvious statement, but the stuff around data transport would be very...is very key and trying to get as robust a set of knowledge there.

I would also argue that like HPO integration probably is not, you know, not that key to kind of some of what we're talking about in terms of clinical care and then exporting of that value set and things like that.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

This is Leslie, I agree with that wholeheartedly. I think computable consent...because of the constraints and opportunities identified in the cohort, however, I would also like to...group's recommendation to make sure that the consent patients are providing are very much plain language, very informed consent because we do want to start a situation where this is just a check the box kind of consent for this very rich...

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Yeah, no...

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Personal information.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

And that's a great point. There is a really great, well, I won't...I think it's a robust discussion about consent and consent models and reports and we really did consider deeply that and, you know, this whole core is designed to be very participant engaged and throughout the entire process including consent and very novel consent models such as the peer model that has been advanced by Sharon Terry as one such example of very dynamically driven and patient engaged consent.

So, no, we've been definitely thinking about such things. I just don't think that it will...and they'll be computable too. I just don't think that an EHR is necessary that we sort of have this linked and develop a standard for...in sort of the EHR realm at this point.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Agree.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, so that I think comes on the next slide. So, that's good, we'll get to that in a little bit more detail in just a second. In terms of what we have here Betsy suggested that we get a more specific list of the standards currently referenced, I think that's good.

I think that the discussion to be tee'd up about the family health history and the implementation of it is another thing.

Under the line standards for genetic data going from lab to EHR you need to name specific standards. Mitra...

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Yes?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Is that something that we will be able to work with you all more specifically to try to flesh out before we get to Tuesday?

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Before Tuesday? The standards for genetic data going from lab to EHR?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Well, just the recommendation.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Oh, yeah, recommendation.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Yeah, what specifically does that recommendation look like, yeah.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Okay. You mean with me not Mollie? Not genetic, Clinical Genomic Workgroup?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Well, just in...yeah, yeah, so in terms of the...right, so you're my...

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Okay, yeah.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

My Task Force Liaison so...

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Okay, yes, I am the Task Force, yes, of course.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

I'm grateful to be able to lean on Mollie and Gil, and whoever else we need to.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Oh, yeah, yeah that's fine, yes, yeah, I can work with them, yes of course.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Fantastic.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

All right. I have one question on this slide actually, on HL7 family health history and pedigree, so the US Surgeon General Office is already using this HL7 model. So, what...like on the other column it says "opportunities to further develop?"

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Maya, do you know what that's about?

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

Yeah...

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Well...

**Maya Uppaluru, JD – Policy Advisor for Health Data Analyst – White House Office of Science & Technology Policy; Division of Science & Innovation – Office of the National Coordinator for Health Information Technology, Department of Health & Human Services**

Oh, sorry, go ahead.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

This is Leslie, there was discussion that there was still large gaps in pedigree and that...but that it was on its way, you know, very much on its way but there could be opportunities perhaps to accelerate this, that was my understanding.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Okay, good, thanks.

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

This is Eric, I...Jon, I don't know how deeply you wanted to get into or how specific you wanted to get on this call so if this is something to take off line or to defer please let me know, but we might want to spend a few minutes on that row three about SNOMED for capturing family health history. Is it...or is that too in the weeds for this call?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

No, this is...like I said; I think this is the right place to...

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

Okay.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

At a minimum get the idea out there and if there is more off line iteration over the weekend on Monday that we need to do that's fine, but, yeah, no now is a good time to approach that.

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

Okay. So, I took the liberty of pasting a little bit of text into the public comment window, I know that's not really what we use it for, but it can be found in the web thing, just to illustrate and declare the issue of pre-coordinating versus post coordinating family history, there is a SNOMED code for gout and there's a SNOMED code for family history of gout and the question is, what should be used and not only are there some EHRs that use one approach and some EHRs that use another approach there are many EHRs including one that I saw two days ago where in actual instance data there may be both kinds of codes within a single patient's family history list which is unfortunate.

So, I think that there is definitely a need for guidance here and whoever is consuming this data is probably going to need to be able to handle both, but I'm not particularly in the loop on which way the pendulum is swinging within groups that are giving a lot of thought to this like the folks who are putting together FHIR profiles and so forth, I don't know if there are folks on the call who are...have their finger on the pulse there, but, again, I think that blowing against the wind here would not be productive and so we want to make sure that we're aligned with...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay.

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

Or the prevailing momentum.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

That's a great comment. Anybody else on the line have thoughts about that at this point? Okay.

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

The other brief point is that SNOMED does have 174 concepts to represent a specific familial relationship like, you know, everything from maternal grandfather to distant relative. So that could be used to represent familial relationships.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

In regards to this conversation may I recommend contacting Jonathan Holt who is an active member of the HL7 Workgroup. He is a medical geneticist and informaticist and actually has done a lot of work in this area where he would also extend your requirement is to be able to express the negation of family history of gout or this patient, although he has gout, does not have a family history of it.

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

Yeah, the negation, yeah.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay.

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

And it might be worth even seeking a formal statement from the HL7, is it the Structured Documents Workgroup? I believe that’s the name of the Workgroup. I think that they are as close to a sort of an authoritative independent body to advise on that question as exists I think.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, all right, that’s totally fair, we can try to, you know, use that one and chase that one down to the ground. Eric, I think I foresee, you know, perhaps a little bit more iteration over the weekend on this, but, I think that is great feedback.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yeah, my question...we have here the HL7 family health history pedigree approach and I think I am correct that the recommendation and the use of that obviously is when you’re recording you would be using the familial relationships and you would also...but for the diseases themselves or the conditions themselves you would be using SNOMED in that.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Eric is that your understanding as well?

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

Yes.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, good, just want to make sure we’re all on the same page. I love when Betsy participates in the calls she makes it so clear. So, okay, very good. Other discussion about the green slide at this point?

And, you know, as you’re thinking about that, you know, I just want to...I think what I’ll feedback to you is that we will bang these into good shape, okay, for discussion at the committee on Tuesday, you know, given that, you know, there’s a little bit of wobble, right, amongst us about some of these things and also given that, you know, there’s a couple of folks that aren’t on the phone, I think we can expect there to be good robust discussion at Tuesday’s meeting.

I think that, you know, we'll probably get to a place where we can't say, this is the complete and, you know, monolithic consensus of the Task Force on these and we won't represent them like that, but I do think that, you know, the...as strong as we can be I think, you know, helps us move with the pace that the whole initiative is moving. So, okay. Going once, going twice on the readily applicable standards? Okay, can we move to the next slide?

Okay, promising standards for PMI. Of course we have FHIR here, the human phenome ontology, computable patient consent, include more complete authorization standards and then addressing the IOM genomics roundtable, GA4GH, work.

Again, I think the framing for this is that, dear PMI we think these are things that you ought to encourage the use of and, you know, more deeply explore their use and development and how that it helps you achieve your standards or achieve the outcomes that you desire, but recognize that some of these are absolutely in flux. Is there any of these that folks, and maybe reserve comment for a second on the computable patient consent, I think that's worth a little bit deeper discussion, but on the others is there anything at this point that, you know, you see that you're either not comfortable saying that about those standards or that there are things that you don't see on here that you think we ought to consider putting on there?

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

I have a question about the, what...just to be sure I understand the meaning of a couple of these, so the "include more complete authorization standards" does that mean authorizing that someone is able, you know, that somebody has the role to use something? Does it mean authentication? What does authorization mean?

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Sure and so, and in contrast of course we had on the...you know, on the green slide, we had OAuth 2, right, so I think that beyond what OAuth 2 does for you there are other, you know, approaches to authorization and other kind of parties are involved with authorization. Are there folks on the phone that want to tee up specific examples for Betsy to think about?

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Hi, this is Gil, maybe I'll mention SMART on FHIR not genomics but just SMART on FHIR in general the platform it actually is pretty widely used if you look at HIMSS and a number of the large organizations Cerner mentioned a digitized forum a while back and an EPIC App Store and so forth and what it does is it encapsulates a number of the standards like, actually the ones mentioned on the green slide, for authentication, single sign-on, you know, those kinds of things.

So, if you're looking for...you see I just mention that because I know you mentioned here build off work of SMART on FHIR genomics, but the overall platform is about how do you enable Apps and so it includes a number of these kind of authorization standards, so maybe just take a look at that, maybe it might be of interest.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Okay...

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Yeah, I would even maybe broaden just to say FHIR...

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yes.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

You know as a transport wrapper for a lot of data and sort of like the Argonaut Project and etcetera.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yeah, I was expecting us to...I was expecting possibly to see a mention of Argonaut on this list.

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

And of note FHIR also has a family history profile for genetic testing.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Does that family history profile, is that a wrapper for HL7 or, I don’t know, I’m not familiar with it?

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

It extends the very basic somewhat limited FHIR profile for family member history to support more robust information appropriate for genetics and precision medicine.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, so it’s...you would then...it doesn’t give you the willies to say “yes we ought to be using HL7’s family health history” but we ought to be testing out the use and implementation of FHIR as an extension, you know, kind of future pathway for how folks relate to that sort of information. Is that...

**Mollie Ullman-Cullere, MBA, MSE, MS – Senior BioMedical Informaticist – Dana-Farber Brigham & Women’s Cancer Center & Partners Healthcare**

Yes, for both genetics and family history.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay.

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yeah and in fact...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

All things data right?

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yeah, in fact FHIR, I mean, it's basically just the latest standard of HL7, so, yeah, definitely. I just want to mention though in terms of FHIR it's different than SMART on FHIR in that FHIR doesn't have the authorization, authentication in any of those items. So, I mean, it's good for transporting data and so forth but like the SMART part that's what builds those standards and that's what Argonaut used, you know, when they added the authentication the SMART was part of that consortium and helped, you know, Josh Mandel for example, helped to make the authentication all those standards that they used for the Argonaut based on the SMART.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yeah, that's why I was thinking we should see Argonaut on this list as well.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Yes.

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Yeah, okay, sounds good.

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

I agree.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

So, I'll take it as a motion that we ought to be adding a focus on Argonaut, right, as a group advancing the use and development of FHIR.

Would it also be fair to try to roll up the authorization row under FHIR or do folks foresee that just, you know, the point being that, is it worth calling out separately that different and more complete types of authorization are important to...for the, you know, tires to be kicked in the Precision Medicine Initiative? Does the group have a sense of that?

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

This is Mitra, I think the way it is right now is correct because there is outside of FHIR and HL7 IHE also has the authorization standard the XUA which is listed here that is already used for some of the IHE profiles including structure data capture from ONC.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay. Maybe what we can do is we can maybe include some cross reference words...

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Okay.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Under each of those recommendations that, you know, includes authorization under FHIR...

**Mitra Rocca, PhD – Medical Informatician – Center for Drug Evaluation & Research (CDER), Office of Translational Sciences – Food & Drug Administration**

Okay.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

And under...authorization includes FHIR so there, you know, hopefully not tautological, but I think they're both important.

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

This is Eric, regarding the human phenome ontology, so I'm not entirely clear on what we're recommending there but it concerns me just a little bit because HPO includes a lot of content, a lot of terms that would be...that would overlap with what might be recorded on a patient's problem list or a visit diagnosis, or findings, things that are under Meaningful Use going to be reported using SNOMED or perhaps ICD-10 CM and so forth.

HPO has the advantage of cross linking to codes and other terminologies that represent specific genetic diseases or genetic abnormalities, or genes but we want to be careful not to recommend anything that's going to require duplicate data entry for instance. So, I wasn't sure what the intent was there.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Oh, so, you know, that's a great point. So, I guess I'll say two things back in response to it. The first is that, you know, I think that what we heard over the past couple of weeks is that human phenome ontology has advantages or utilities that are not found in currently available standards for the purposes of precision medicine and therefore it ought to be looked at or considered in terms of the initiative more broadly and tested out and see how it fits.

But the second thing, I guess I would say, is that, you know, we're not...we would not want to signal at this point that we think that this might be a good replacement for things that are in green right now but that we say that these are available and these ought to be used. That, you know, there is a reason why those are, you know, there and that part of the, you know, testing and development that needs to happen is to ensure that there is adequate mapping to the standards that are going to...we think ought to be promoted for use so that you do avoid that issue of duplication and so that would be my quick response to it and how I feel about it.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yeah, I think we probably don't want to use mapping so much as we want to use connections between the different levels there and the different vocabularies. We don't want to...

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

Okay.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yeah.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Yeah, yeah, yeah, yeah I know the heartburn with...so that's a good point, all right.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

And at least at the degree of synonymy it's going to be represented for people in the UMLS meta source because HPO is going in there.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Yeah.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

So, Eric, does that make you feel better?

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

Yes, thank you. I suppose...

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

This is Leslie and that applies to any of these recommendations we're not looking at replacement to existing standards being used, we're looking at how the things needed to be added to support...

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yes.

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

The cohort.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

And then...

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

Yeah, I think as we maybe get to the next turn of the crank in terms of specificity of recommendations they'll be recommendations as to what EHRs should be required to capture versus recommendations about what the data store for the cohort ought to be able to ingest. So, you know, you can probably...HPO might fall perhaps into the latter but not necessarily the former.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Wisely stated Dr. Rose, I think so, good. Okay. Any other discussion on...that's a great discussion about these and that's shaping up, that makes me very happy the way it's shaping up. Any other discussion about the yellows at this point? Okay. Can we move to the next slide?

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Oh, I just want to make one comment and...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Sure.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Sorry, want to make one comment about the yellows, the business about the common consent, etcetera, this is an area where I agree with I think what Josh said and also related to what's going to be happening with the revision of the common rule and so forth, but I think that the discussion of the elements that are required and the best way to represent them in, you know, systems and whatever can be handled parallel, maybe not initially, integrated with the EHR, but I do think that this may be a way where...a place where the PMI standardization needed for the PMI might be able to be worked back into EHR because I think that even in local systems people may very well want to capture information about what the patient has consented to let happen to their data.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Yeah, yeah, no, I think that's exactly right and for me this is where, you know, I kind of ascend out of the cloud level of EHRs and get that kind of, you know, broader vision of how...broader space of health IT, you know, which is, again, you know, the wheelhouse...that's a great point.

I think we will look to work more closely with Leslie, I think that was a good, you know, set of brief discussions that we had about computable patient consent and we'll try to get that into good shape for discussion on Tuesday. So, okay, moving onto the red slide.

Okay, standards gaps for precision medicine, there is computable patient consent right there, so, again I think that's an area for more discussion, race and ethnicity, minimum datasets I think, you know, that I would flag to say that that's something we'd want to work very closely with our colleagues at NLM and NIH in terms of defining that, and then finally microbiome data standards as Josh called out appropriately. With that caveat that I just gave you any additional thoughts about these items under standards gaps?

**Leslie Kelly Hall – Senior Vice President of Policy – Healthwise**

Jon, this is Les, and we did get some advice at the last Standards Committee about gender and that was some recommendations coming out of the Interoperability Advisory Group using the Fenwick Institute's model for gender identity. So, just adding that there that actually might be in the yellow versus the red, but let's be consistent from each recommendation around what's coming out of the Standards Committee already.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, that's a good one. I support that. Other folk's thoughts about that? Okay, all right, so we'll work to make that adjustment. Other thoughts about the standards gaps?

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

Jon, one of the things that came up, this is Eric, one of the things that came up in our discussion was dbSNP and the enormity of dbSNP and the constantly changing nature of dbSNP, so it represents a standard that is an outlier in that regard in that no system could be expected to necessarily contain within itself without some sort of way of querying some outside repository the ability to get the meaning out of a dbSNP identifier.

So, it's not so much a gap in the standard as it is perhaps a gap in ability to access the information in a standard and I wonder if that perhaps should be called out that if there were, and perhaps there is and I just don't know about it, but if there were some kind of, you know, web API where somebody could just say, here's a dbSNP identifier give me back whatever information is available about this polymorphism that, you know, that would be potentially essential for being able to drive the clinical decision support on that level of genomic data that's a little bit sci-fi perhaps but it might be still worth calling out as a gap.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

I like science fiction. Science fiction is good I think that's a cool suggestion. Josh, did you have...if you're still on, did you have thoughts about that?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Sorry...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Oh, there you are.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

I just had to step away real quick.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Yeah, yeah.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

What was the question?

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

So, the idea...well, we were talking about standards gaps and I brought up the fact that with dbSNP there is not so much a gap in the standard but a need for a new way to access a standard traditionally with a standard you can store all the codes and terms and descriptors, and so forth within an EHR or other systems database with dbSNP it's simply not feasible because it's so huge and changing every day. So, that there is sort of gap in the ability to retrieve the information associated with an identifier from that standard and that would be a useful...

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

So, basically...okay, so I think you're basically saying I'm going from a SNP to a set of, you know, sort of an understandable set of metadata about that SNP that could be integrated...

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

Precisely.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Into and EHR from dbSNP, yeah. Yeah and I would say sort of extend that and say, you know, I think as we develop sort of more maybe clinically...and dbSNP aggregates from all over the place. If you think about like ClinGen and ClinVar, you know, but I think, especially ClinGen, develop maybe we need to make sure those have, you know, hooks that are going to be readily integrate able and, you know, sustained to EHRs. Because that's a good point.

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

Yeah.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

And when you think about action ability and metadata that's probably, you know, that's probably where the rubber will meet the road and it could actually directly, theoretically, support CDS as a downstream consumer of the information.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, so let's add that to the list, I think that it's a good one to kind of at least put out there. I'd be interesting in pursuing it, you know, ultimately. So, other thoughts about the gaps that we want to have on there that we don't? Okay, could we then go to the final slide, the accelerator slide?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

And...

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Oh, Josh, did you want to say something?

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Yes, sorry, I'm going to have to probably step off, but I'm certainly happy to continue to coordinate by e-mail.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, thank you so much for the time and effort, and the extra time that you gave us, I really appreciate it. I know we're going long.

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

No, no, no.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Okay, all right, thank you, all.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

And this...

**Joshua C. Denny, MD, MS, FACMI – Associate Professor, Departments of Biomedical Informatics and Medicine – Vanderbilt; Office of the National Coordinator for Health Information Technology**

Thank you, Jon and Leslie for all your great leadership.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Oh, my pleasure.

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Yes.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Was there somebody else?

**Betsy L. Humphreys, MLS – Deputy Director – National Library of Medicine**

Here, here, Jon, I have to...this is Betsy I have to go to another PMI meeting now.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Excellent. Okay, well then let's, thank you, I understand that folks are going to drop off, let's real quick just any quick comments on the accelerators? I think these are a good set of ones in here at a minimum for discussion but maybe for more than that, you know, why don't...including the dbSNP that's on here as we had just kind of previously discussed. So, any quick comments, anything that is a major red flag for folks to have on here for discussion?

Okay and I'm sorry I know this feels like time pressure is kind of cooking on us. I think it's a good set. If there is any off line comments that Task Force members want to share between Maya, Mazen, Leslie and myself we'll absolutely take them.

So, let's go to the next slide and I think we're at the place...okay, so next steps, just quickly, we're going to take all this excellent feedback, we're going to try to bang these into good shape over the weekend. I think on Monday Task Force members we will try to get this circulated to you.

I'm not sure if we're going to have time to be able to get any final comments before we share it out on Tuesday, we will discuss and let you know kind of where we land with that, but I am, you know, Leslie and Maya, and Mazen and I are so grateful for the wonderful effort and feedback, thank you so much for helping us get this to where this is and again I know this has been fast but I think this is going to be really helpful for the Precision Medicine Initiative. So, with that let's call a halt of discussion and Michelle I think we're at a place where we generally ask for public comment next, yeah?

## **Public Comment**

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

Yes. Lonnie can you please open the lines?

### **Lonnie Moore – Meetings Coordinator – Altarum Institute**

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

### **P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

And...

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

While we wait for public comment...

### **P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Yeah.

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

Sorry, there...Eric had left some comments in the chat so we'll share those with the group.

### **P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Perfect.

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

And we also had a comment from Rita, I'm going to butcher her last name, Torkezadeh, and she has a question more than a comment "I'm not entirely clear on the term computable consent that is being used is that the same thing as electronic consent?" So, we may want to clarify in the final recommendations.

### **P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

Good.

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

And we have no public comment.

**P. Jonathan White, MD – Deputy National Coordinator – Office of the National Coordinator for Health Information Technology**

All right. Leslie any parting words if you're still with us? All right, she's not, so, you know, what I'll say, what the folks and the public didn't know is that right before the phone call Leslie had to engage in first responder activities and perform CPR on somebody in the Starbucks where she was so thank you Leslie for continuing to remain engaged and for your public safety efforts.

Folks on the Task Force thank you so much on behalf of Maya and Mazen we're so grateful for the effort that you put into this and we're looking forward to a great discussion on Tuesday. I think we've tee'd it up really well for them and I think we'll have a great time. So, thank you very much everybody and look forward to talking to you next week.

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

Thanks, Jon.

**Gil Alterovitz, PhD – Assistant Professor – Harvard Medical School & MIT**

Bye.

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

Bye.