Department of Health and Human Services
National Committee on Vital and Health Statistics (NCVHS)
In conjunction with the National Library of Medicine

Expert Roundtable Meeting on

Health Terminologies and Vocabularies

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P R O C E E D I N G S (9:05 a.m.)

Agenda Item: Welcome and Morning Goals

DR. STEAD: Welcome. I am Bill Stead. I really thank all of you for being here. As a federal advisory committee, we need to start by letting each of the members introduce themselves and indicate whether they have conflicts of interest.

I am Bill Stead. I am from Vanderbilt University. I am chair of the Full Committee and no conflicts.

MS. KLOSS: Linda Kloss. I am a health information management consultant. I am a member of the Full Committee, co-chair of the Privacy, Confidentiality, and Security Subcommittee, member of the Standards Subcommittee and I have no conflicts.

MR. ROSS: Dave Ross, member of the Full Committee, member of the Population Health Subcommittee, Emory University and the Task Force for Global Health, and I have no conflicts.

DR. PHILLIPS: Bob Phillips, American Board of Family Medicine, Georgetown University, Virginia Commonwealth University, member of the Full Committee, and co-chair of the Population Health Subcommittee, no conflicts.

MS. GOSS: Alix Goss. I am with Dynavet Solutions, working there in a consulting division, Imprado. I am a

member of the Full Committee. I am a co-chair of the Standards Subcommittee and I have no conflicts.

MR. COUSSOULE: Nick Coussoule, BlueCross BlueShield of Tennessee, co-chair of the Standards Subcommittee, member of the Full Committee, member of the Privacy, Confidentiality, and Security Subcommittee and I have no conflicts.

DR. MAYS: Good morning. Vickie Mays, University of California, Los Angeles. I am a member of the Full Committee, Populations and Privacy, Confidentiality, and Security.

DR. CORNELIUS: Good morning. Lee Cornelius, the University of Georgia, member of the Full Committee and the Population Health Subcommittee, no conflicts.

MR. LANDEN: Good morning. Rich Landen, member of the Full Committee, member of the Standards Subcommittee, no conflicts.

DR. STEAD: Debra, are you on the phone?

MS. STRICKLAND: Yes, I am here. Debra Strickland, XeoHealth, member of the Full Committee and member of the Standards Subcommittee, member of Population Health and no conflicts.

MS. HINES: Good morning. Rebecca Hines. I have been in email contact with all of you, delighted to finally meet you. I am the executive secretary for the Committee.

DR. DORSEY: Good morning. I am Rashida Dorsey. I serve as the executive staff director for the National Committee. Thank you.

MS. DOO: Lorraine Doo, Centers for Medicare and Medicaid Services, Division of National Standards, Lead Staff for the Standards Subcommittee.

MS. BEBEE: Suzie Bebee, ASPE, staff to the Subcommittee.

DR. LINCOLN: Mike Lincoln from VA and University of Utah, staff to the Subcommittee.

MS. SPECTOR: Nancy Spector, American Medical Association.

MS. DILLON: Michele Dillon, Rose Li and Associates.

MR. RICHARDS: Gregor Richards, Rose Li and Associates.

DR. STEAD: Just as a reminder for invited participants, in a little bit, we are going to want you to introduce yourself and answer the question in about 30 seconds of what you are hoping we accomplish. You can be thinking about that if you have not already been doing so.

The National Committee is charged to study issues that are related to the adoption of uniform data standards for patient medical record information and the electronic

exchange of the information and to make recommendations to the secretary regarding those standards.

We also advise the department on health data collection needs and we review and monitor the progress and opportunities of those needs as most of you know.

As you all – laid out in the environmental scan. We did a lot of work in this space in the late '90s and early 2000s. We have not done much since and a lot has changed.

We thought that the time had come to really step back and try to assemble a fact base of the current state of the way this work has evolved and then a symbol expert to really rethink or take a fresh look at what we might do.

We started working on this well over a year ago. We began using panels in our Full Committee meetings to begin to build an understanding of the committee really about the state of play. We had the good fortune that this work and the National Library of Medicine's updating of their strategic plan came together and Dr. Patty Brennan saw the opportunity to work with us to try to get a fresh look at this area. She charged her team to help work with us as staff to the committee to bring this together. We will introduce them later, but I wanted to just take this moment to thank Susy Roy and Vivian Auld for just working weeks and weeks and extraordinarily, collaboratively with

us to build the environmental scan that you have in front of you.

The goals of the Roundtable are enumerated on this slide. From the beginning, we felt that once we assembled a shared fact base, we really needed to assemble the key experts. We are blessed that so many of you were able to respond to the invitation and join us for this. We really do have the right types of minds from the right perspectives to both know where are and to think about what we might do that could maybe begin to make things work better for everybody over time.

What we are hoping to do is make sure we do in fact have that common understanding. We are then trying to identify, as we go through the course of the discussion blocks, opportunities for near-term improvements. Many of the things we might do will probably take time. It appears to be that there are some things we might could just do. I think that would be helpful.

We want to discuss opportunities to improve governance and coordination across the different standards. It is not that we do not have that within the different efforts, but we are trying to think how we might do that better across the areas and to really identify also the top priority gaps in coverage. That is the specific interest of

the NLM and then to envision a roadmap for introducing improvements in updates to standards.

It is time for each of you to tell us in a short introduction who you are, who are you affiliated with and what you hope by the end of this meeting we will have discussed. We are not including members in this. We really want to hear and learn from you. We did our brief pieces. Let's go table by table.

Agenda Item: Introductions

DR. BLAKE: I am. Dr. Kathy Blake and I am with the American Medical Association and oversee the health care quality efforts as well as our improving health model initiative clinical group.

What I would like to see at the end of the meeting is some clear lines of sight for collaboration between the different standards groups and terminologies so that we use scarce resources well and minimize redundancy and maximize clinical value for patients and physicians.

DR. ROMANO: Good morning. I am Patrick Romano. I am a general internist and general pediatrician by training based at UC Davis School of Medicine in Sacramento, California. I guess I was nominated by NADO, and I bring a perspective as a data user with a focus on health services research and quality improvement. Among multiple roles, I am co-editor-in-chief of the academic journal called Health

Services Research, HSR, which publishes a lot of work using patient medical record information. I also have been involved in developing, validating, and applying quality measures in a variety of settings for a variety of clients. I have served on one of the topic advisory groups for ICD-11 and have been actively involved in proposing updates to ICD-10-CM as well. I hope to promote increased use of and value of the terminologies that are under discussion today.

DR. NARCISI: I am Jean Narcisi and I am director of dental informatics for the American Dental Association. I have been involved in the standards world for a very long time.

I guess what I am most interested in and hoping by the end of the day is that we will be able to identify some solid opportunities for the United States and the world to identify ways in which there can be more interoperability through our vocabularies.

DR. CHUTE: Chris Chute. I am from the Schools of Medicine, Public Health, and Nursing at Johns Hopkins. I have also been among other things chair of the ICD-11 revision work at World Health Organization.

I guess what I aspire to see is something that I had hoped for 30 years ago when we had these meetings and that is a tighter integration of information models and vocabulary content. Now that we have fire, now that we are

in the next generation, if you will, of information models, how we bind vocabularies and how we use them is going to be increasingly important to the effective interoperability of data because if we take only a vocabulary perspective, we are missing the embedded semantics and information structures.

The other aspiration I have had is the promise of translational medicine. I am co-PI of the Center for Data to Health across all the CTSAs for informatics integration among other things. And the promise of leveraging basic science information and discovery to fundamentally transform and enhance the future of health care is again dependent on consistent semantics between what I call the semantic chasm of despair of basic science and clinical science and to the extent that we can bridge that will have achieved success.

MR. MCLAUGHLIN: I am Patrick McLaughlin. I am the head of Terminology QA and User Services at the National Library of Medicine. Our group puts out RxNorm and the UMLS among other things.

At the end of this meeting, I am hoping we discuss some of these gaps in the terminologies and vocabularies and maybe some steps forward for identifying these gaps and addressing them.

MR. ARGES: My name is George Arges. I am the senior director of Health Data Management at the American Hospital Association. I also chair the National Uniform Billing Committee.

One of the take-a-ways I would like to see is really developing a framework that clearly articulates a level of co-existence among the different medical terminology so that you can develop the necessary integration through a variety of different methods. Today we are faced with increasing electronic exchange of information, but it somehow loses the translation when we are moving from one side of care to another side of care. We need a framework that allows that co-existence to occur as well as a systematic methodology for insuring updates to medical terminologies and vocabularies.

DR. MCDONALD: I am Clem McDonald from the National Library of Medicine. I am sort of an ancient in the standards world. I am kind of excited because the way FHIR has been adopted and it has some discipline inside of it, I think we might finally get it done while I am still breathing. I am hopeful about that.

But I also think the focus on vocabulary and terminology is a bit narrow because what goes into the fields that we transfer our codes and their code systems and most of them have words or names with them, but there

are things like RefSeq for genetics. It is not exactly a name thing or dbSNP, which has 300 million records. But you have to get those right too if we are going to transfer the status. I think we need to expand a little bit of our view from just names and words to code systems.

MS. AULD: I am Vivian Auld from the National Library of Medicine. I was one of the people who helped write the E-Scan. I am mainly interested in hearing what everyone has to say.

MS. LEON-CHISEN: Nelly Leon-Chisen. I am director of Coding and Classification for the American Hospital Association, the executive editor for Coding Clinic for ICD-10 and ICD-10-PCS and Coding Clinic for HCPCS. I am also on the editorial board for the CPT assistant.

I can say that I have also been at this maybe just as long as Dr. McDonald. There is a picture in a closet somewhere. I have not participated in these discussions in preparation for ICD-10.

What I would like to see is that whenever there is a need to migrate to whatever the future is going to be that we do not take another 30 years to figure out whether we want to do this or not. I am hoping that there is discussion of continuity, transition, succession, whether it is the code sets or the individuals that lead the process because I think that many of us at some point in

the future will be retiring. I would like to save the next generation all that work that we did to get to ICD-10.

MR. MENNING: I am Matt Menning from the American Medical Association. I direct engagement for something called the Integrated Health Model Initiative, but spent most of my career the last 20 years working with CPT. I cannot imagine a better place to close out that work than with this discussion. I am excited to be here.

I am also at the point I am afraid where I start just repeating what other people have already said. I echo the sentiments of my coworker Dr. Blake. Tighter integration, less duplication between standards that are in use domestically and globally. I echo what Chris and Clem had to say. This conversation needs to be a little bit broader than just the words that we use to describe these things.

And then we will reiterate a point that Kathy made. I think as the AMA, it is important to us that the voice of the clinician is squarely present as we develop these kinds of tools and terminologies.

MS. BOWMAN: I am Sue Bowman, senior director of Coding Policy and Compliance for the American Health Information Management Association. I have been involved like Nelly for a very long time in some of these discussions. I serve on the Coding Clinic, EAB for the

Editorial Advisory Board for both ICD-10-CM/PCS, and HCPCS. I also participate in the CPT Editorial Panel discussions and am also a member of the ICD-11 Morbidity Reference Group.

Nelly and I have been together a long time. We did not actually both discuss at all at breakfast today what we were going to say in answer to this question, but we were both very involved in the transition to ICD-10. Similar to Nelly, what I am hoping for is a discussion of a more streamlined process to update to a new version of a code set so we do not have to go through the very arduous, very painful transition to ICD-10 the next time around with ICD-11. While I expect I will be long retired, maybe long dead by then, I would like to see that my successors do not have to go through quite that same process to get us to a new more up to date concept.

DR. CIMINO: Good morning. I am Jim Cimino. I am a country doctor from Alabama, practicing physician, professor of medicine, University of Alabama at Birmingham where I am also the director of the Informatics Institutes. I spent a lot of my professional career trying to define what makes a good terminology and figuring out ways to create and maintain terminologies that adhere to those principles.

I am here because I want to see what I can do to steer us away from a world where clinicians are recording things for secondary purposes like billing and instead recording not just the problem list and their medications and other orders, but the full spectrum of information about their clinical reasoning in ways that we can reuse for billing and for research and all these purposes, but primarily for improving patient care.

DR. STEAD: For those of you that did not recognize the connection, Jim was channeling Octo Barnett with his country doctor from Alabama.

MS. LIPON: I am Shelley Lipon. I am the head of global customer relations for SNOMED International. I am here I think to echo a lot what has already been said. The tighter integration between the many standards that exist out there. The one thing that I hear all the time from the actual users of the standards is that is there is too many we do not understand how they all work together. I am hoping that this meeting will help us.

MS. WIGGS-HARRIS: Hello everyone. My name is Wylecia Wiggs-Harris. I am the relatively new CEO of the American Health Information Management Association. I come to this with fresh eyes. And what I am most interested in is for the opportunities for simplicity and that we do not

make this overly complex and where are the opportunities for us to continue to streamline.

MS. SKURKA: I am Margaret Skurka. My first meeting here. I am professor emeritus at Indiana University Northwest. I have been involved in AHIMA kind of HIM work all my life and currently am consulting. I was happy to see some discussion about 11 and I hope we do that and have a few tangibles. I also am frustrated by the 23 years that it took from when we published 10 until implementation, longer than any other major country in this world. We need to be better at that.

And then we have that big report that all of us were reading when we were flying here to yesterday. Content gaps and standards and so on. I want to come out of here with tangible, with action items, real improvements that we can make in standards, coding systems, communication, et cetera.

MR. HAMLIN: Good morning. I am Ben Hamlin. I am a lead research scientist in the Performance Measurement Department of NCQA. I am also the lead architect of the HEDIS ECDS standard, which just introduced a new patient-centered model for HEDIS digital reporting. We need terminologies.

What I would like to see here today is a discussion of maybe a preferred set or a preferred grouping

of at least a minimum number of vocabularies that help us phenotype patients to help get to patient-centered care understand what specific characteristics that would inform what sort of care they should be receiving. It is a mad house right now. I do not think there is really a good set of agreement on what those might be. I would like to see some discussion around that.

MS. ROY: Good morning. I am Susie Roy from the National Library of Medicine and one of the co-authors on that report that you all read. Thank you for the comments that have come in so far.

I echo Vivian in that I am hoping to learn from all of you today, learn from your expertise and gain some wisdom and also see where the discussions go over the next few days.

MR. MOSCOVITCH: Good morning. My name is Ben Moscovitch. I direct the Health IT Portfolio at the PEW Charitable Trust, which is a large nonprofit here in DC. I am hoping today that we talk about some tangible opportunities that the Office of the National Coordinator for Health IT has to advance and encourage the adoption of standards specifically through the Trust Exchange Framework, the development of regulations on APIs and other opportunities that may come up in the not too distant future.

DR. YONG: Hi. I am Pierre Yong. I work at the Centers for Medicare and Medicaid Services and the Center for Medicare where we work on payment issues. Much of what I have been thinking has already been said so I will not echo that. But I am looking in particular to the roadmap –

PARTICIPANT: (off mic)

MS. KUEHN: Hi. I am Lynn Kuehn. I am president of Kuehn Consulting and a health information management professional. I work – of procedure coding with both CPT and ICD-10-PCS. My major concern is modernizing the maintenance process for the ICD code sets to streamline that process.

MR. VREEMAN: Good morning. Dan Vreeman. I am a physical therapist and the director of LOINC and Health Data Standards at the Regenstrief Institute, Indiana University School of Medicine.

Having read the briefing reports and knowing what everyone has said, I have no doubt that we are going to have lots of fun discussion about details, governance, version updates and so forth. I guess my hope is that we do not lose sight of or we believe the value of standardized terminology is both at the level of the nation, individual health care organizations and the patient if we think about whether it is worth investing and how much we should invest both for developments and implementation of these without a

clear sense of why and what we are going to benefit from it. I think maybe that is more for our messaging out of this group. But I do not want to lose sight of the why that this is important for enabling the healthier state that we want.

DR. WHITE: Hi everybody. I am Jon White. I am the deputy national coordinator for Health IT at the Office of the National Coordinator for Health IT. I guess if I had claims to fame in this domain, it would be I was co-chair of the Health IT Standards Committee for a while, which is another HHS advisory committee. I was party to the original NPRM for ICD-10 back in 2008. That was fun.

Before we leave, I hope we discuss the answer to life, the universe, and everything. Don't panic.

MS. PICKETT: Good morning. I am Donna Pickett, National Center for Health Statistics, CDC. I am the chief of the Classification and Public Health Data Standards staff at NCHS. And obviously many of you know me through ICD-10-CM. I see a lot of smiling faces. I have also been very active with WHO in the work and development of ICD-11 and have worked very closely with several people in the room including the person sitting to my left, Dr. Chris Chute.

DR. STEAD: I think I will turn it to Linda. Before I do that, I just want to tell you that Linda has

been awesome in pulling this together. I can promise you that one thing we have is a well-organized day. Thank you, Linda.

Agenda Item: NCVHS Health Terminologies and Vocabularies Project and Roundtable Design

MS. KLOSS: With this kind of brain trust, I know we will break through any barriers including any imposed barriers on agenda. We have a limited amount of time and the right people in the room so we are determined to press along.

I want to just say a few words about the committee and how it does its work because you have heard as we have introduced ourselves a bunch of subcommittees. For those who are not aware, the NCVHS does do its work through subcommittees and word products go to an executive committee. We also have a special review committee that stands by to look at progress on standards and then to the Full Committee for approval.

As highlighted in gold, this work is work of the Standards Subcommittee. You have met Alix and Nick. You will hear from them tomorrow.

One of our goals going forward and I think this is very relevant in light of what you said is that we want this work to converge with work that the Standards Subcommittee is doing to develop a predictable roadmap for

standards. We do see a convergence between our thinking on terminologies and our thinking on other kinds of administrative standards that are also part of the charge of the committee.

We have with us today members, as you heard of other subcommittees. We have half the Full Committee here and the kinds of recommendations that come out of today will have an educated audience as they work their way through the committee.

We have been on a bit of a journey. As I have said to a few of you, we really could not launch this kind of terminology and vocabulary initiative until just about now, but we feel like this is really a good time. We have come through the pain, as you have heard, about ICD-10. We are looking at predictability roadmaps and rationalizing how we make changes and how we leverage the work of all of these groups to support interoperability.

We started last year. We developed a scoping document for this initiative. We have done a couple of briefings for the Full Committee. We have engaged through a project support agreement with the National Library of Medicine. We prepared the environmental scan. We knew full well we were going to have this expert meeting at this point and here we are. This is an important milestone for the committee.

Once we finish this, our goal is to complete the environmental scan, present that as early as the September meeting of the committee, get it approved, get it posted for the broader audience, and actually begin to draft recommendations, practical recommendations, as you have noted, near-term recommendations while we are continuing to look at where this might go in the longer term. We share your thought of separating the things that are possible to do or recommend near term with the continuing thinking of the larger transformational agenda that may take a little more time.

As the committee does letters, it also does reports. We have an upcoming 14th Report to Congress and HIPAA that we want to incorporate themes that come out of this meeting. We want to through listening to you understand what the longer term agenda is. I hope that reinforces how important your input and your work today and tomorrow morning is to the path ahead. Again, we appreciate and thank you in advance.

Just a brief word about our agenda and how we have well organized the work. We knew that with a group as rich and diverse and expert as this that we were going to get most of the thinking out if we could allow you each to contribute directly. We are going to use this breakout group format liberally today. Just today.

We are going to take you through a little short review on the environmental scan and get any high-level feedback and then we are going to go right into a breakout discussion on what we can do to improve maintenance and dissemination and what principles should guide it. We are going to start with the mechanics. Then we are going to move to adoption and implementation issues.

And then our final breakout this afternoon will be on governance and coordination. We think we need to prime the pump to get us to thinking about governance. Our logic is to kind of go from maintenance to adoption and then to overarching governance, both short-term changes, things we can do perhaps early on and then perhaps things that are longer term.

Nothing is off the table. Any idea is good. You will see as we structure the breakouts, we are asking for specific consensus around some key questions and then we are asking for your big picture aha's that will become part of the fabric of the report that comes out of this meeting.

Tomorrow we are going to focus on gaps. I know that is an area of interest. We are going to preview ICD-11, which has now been released. We are going to come back to this issue of how do vocabulary and terminology standards as they evolve interlock with the predictability roadmap work. And then we are going to ask for your final

thoughts on what path this initiative should take next. Be thinking about recommendations you might make to the committee on what we should be focusing on next here that may not be on our radar at this point. We are going to ask before we conclude for your final thoughts and recommendations. This is a very fast moving action packed day and a half. I assure you. You will not be bored.

We have a special guest coming from the Canadian Institute for Health Information. Her flight was cancelled last night. She will be joining us later today. But she is just going to share how Canada has organized the management of ICD and the coordination. We know we have some that are also aware of what Australia and other countries are doing. We want to have some of that dialogue before we go into discussing governance this afternoon.

A couple of ground rules. We have a process at NCVHS of raising our tent cards when we want to talk. Just standing them on end. That will help our speakers although most of the discussion will be in the small group so you do not need to deal with tent cards. You will just talk it out.

We do ask always that you speak into a microphone, not when you are in the small group breakouts again, but when we are reporting out from the small groups because we are recording this. There is a transcript of

this meeting. There will be a published transcript available. The breakout discussions are less formal.

Our chair and his side kick here – we kind of reserve the right to move us along and stay on topic and stay on schedule. We will be bullish on that.

Because you have such a wide range of perspectives, we all encourage one another to listen carefully and learn from one another. That is about it. Any questions on logistics?

When we break for lunch, if you have not been in this building, there is a cafeteria one floor up. It is fine. We do not have time to go anywhere.

DR. STEAD: Steve, would you mind reading yourself in and saying who you are, what your affiliation is and what you hope to get out of the next two days?

DR. BROWN: Sure. My name is Steve Brown. I work for the Department of Veterans Affairs in Vanderbilt University. I direct the Office of Knowledge Based Systems in VA where we are responsible for things such as terminology, decision support, interoperability, standards and sort of the technical end of the informatics pool.

And what I hope to get out of the next couple of days is an understanding of the common understanding of where we want to be. I think if we do not have that common

understanding, we are going to have an awfully hard time getting there.

DR. CLARKE: Good morning everyone. I am Diana Clarke. I am the deputy director of Research for the American Psychiatric Association. I am also the senior research statistician and epidemiologist with APA. As part of my work, I work on DSM-5, a lot of things DSM-5 and work with a small group that is actually trying to come up with common terminology for mental health issues and in addition to that, also work on developing our National Mental Health Registry where we want to try and get all these common terminologies and common data elements within the registry so we can actually capture the right thing when we are actually doing some of our research and just inform clinical care.

I am with the person that just spoke especially when it comes to mental health. The terminology – it is such a mess. I would really like to see us come to the common understanding of the different terms.

DR. STEAD: Thank you very much. Is anybody on the phone from our invited participant list that needs to introduce themselves and tell us what they want to achieve or are all in the room? We are good.

DR. MCDONALD: Is there any standard passwords to get on the standard Internet here?

DR. STEAD: I plead my standard ignorance. We have someone coming to help.

It is my pleasure now to introduce Vivian Auld and Susie Roy. Vivian is the senior specialist for Health Data Standards and Susie is the SNOMED CT Coordinator at the NLM. While they are coming up, let me just give you some context about how the committee has used environmental scans. We have done three in the last couple of years. In June of 2016, we released one on demands and indicators to inform development of a new measurement framework for assessing community health – the health and vitality of communities.

In December 2017, we released health information privacy beyond HIPAA, a 2018 environmental scan of major trends and challenges. And then in January of 2018, we released vital records and vital statistics in the United States, usage, users, systems and sources of revenue.

Our attempt when we begin to get into a very complex area is to bring together in essence a fact base that can serve as a platform from which we can consider alternative results in recommendations. We do without trying to get into rights and wrongs of different opinions. We do try to include a spectrum of the comments that people make about the types of things that might be improved in the scan. It is not pure fact. It is a mixture of fact and

the representative sample of opinions we think might help – consider alternatives. We do not try to argue them out in the environmental scan. But this has proven to be a very helpful tool for the committee and I think it is slowly turning into a set of very useful resources to the community.

With that brief introduction, would you like to introduce us to the scan?

Agenda Item: Highlights of Environmental Scan Report

MS. AULD: Sure. Hi. I am Vivian Auld. You already knew that. First of all, Susie and I wanted to thank you for all of your comments again and reiterate again and again if you have any more comments, if you see anything where we have made a mistake, we definitely want your feedback. We want your corrections. Please do not hesitate today, tomorrow, next week, whatever.

Just to take you through the document, we started off giving you the brief purpose and the scope of this document. One of the things that we focused on was the fact that we do not have transaction standards included in here. It is a very scope. But we did give you a list of all the definitions for the things that we have in here and a background of who are the players, what are the processes that we went through in order to get where we are today. As

everyone has been saying, it has been a long process with many different manifestations.

Also, we get into the – I had notes here, but I am wearing new glasses and I cannot read my notes so that is why I am not reading them.

DR. STEAD: Can I make a comment? I just wanted to point out one thing in the definitions because we clarified it between Version 2 and Version 3. It is specifically around the concept that when we are talking about terms, we are not talking about words only. The definition that we have now put in is a term, is a word, a concept or notation that has a precise meaning in some uses or is particular to a science, art, profession or subjects.

For the purposes of this scan, terms are not limited to words, as combinations of letters and numbers may constitute scientific names. That is an attempt to clarify that we include those as terms that can then be included in standard terminology set. That is part of the scope in the current version of scan, clarified in response to comments we get to Version 2.

MS. AULD: Definitely. The other thing from the definitions that you should note is that while we are talking about naming standards, we are focusing on HIPAA and what was formerly Meaningful Use, and what is now

called Promoting Interoperability, which again going through many manifestations of what it is.

And then we also talked a little bit about the various gaps that we go into. We were thinking that there are potential solutions that people have been talking about. The three that we focused on are the fact that you can take an existing standard and you can expand it. You can name a new standard, add them to the long list of what is there, or you can develop a new terminology.

At NLM, we always recommend whenever possible build on the existing. Do not create something new. Do not name something new. But we are hoping that maybe you have some other ideas for ways that we can approach this and especially those of you who were talking about ways to focus on the interoperability. That would be good to hear more about that.

MS. ROY: Looking at this as kind of Part 2 of the environmental scan where we took a little bit of a deep dive into the maintenance and dissemination of the standards. We looked at the adoption of the standards and the governance and coordination of the standards.

Within these sections, we really wanted to take a more general approach where we looked at the support for users. We looked at the overall strengths and the

weaknesses in the collective and the overall impact that these have on really the stakeholders.

Really these are the three main parts of the discussions – will lead the discussions that we will have today. If anyone has any general overall kind of comment, we will take it now, but these will be what we are going to focus on primarily mostly for today.

And also within this part, we pulled together some themes for evaluation in improvement. I believe that that is going to be for tomorrow. That is going to be the main discussion for tomorrow. If you have not looked at those carefully, we advise maybe look at those tonight and especially after some of the discussions that we have today surrounding the maintenance dissemination, the adoption and the governance and coordination. That way tomorrow we can really hone in and look at these overall themes that we have defined and laid out, but then also hear your thoughts on those themes so that we can move this forward.

And then for the last part, the appendices. Appendix 1 and Appendix 2 are really where we went into the deep details on the name terminologies in Appendix 1. And then additional health terminology standards for Appendix 2. I do want to let you know that really we had some common – we wanted to use or we wanted to focus on terminologies that were commonly used because there are so many

terminologies, vocabularies, code systems. Everyone has their favorite. We really tried to look at those that were commonly used here in the United States so that we would not have a whole document that was over 300 pages for you guys to read. We kept it at around 100 instead.

There are probably some that are left out in that Appendix 2. If you think that they need to be described and evaluated, please let us know and we will be sure to include that. We did not omit any maliciously. We needed to cap it at some point.

And then Appendix 3 and 4. We want to also let you know that we did include the 2000 Guiding Principles for Selecting PMRI Standards that was issued by the NCVHS. Really we wanted to again say that the work that you do today and tomorrow is designed to enable the committee to identify the areas that are possible for update and moving forward.

DR. STEAD: We do not really want to go into questions about the specifics of the content, but we would like to have questions if there are ones around the kind of content that is in it and what has guided us in putting it together so that people know what they can look for in there. Our real purpose is to make it approachable to you. I think we can then move ahead.

MS. KLOSS: Thanks again to Susie and Vivian. I think we all found we learned a lot in the course of just pulling this together.

I am happy to say that we have just gained ten minutes. This is good. We will need it. I think there is no reason not to just dive right into our first breakout and let the discussion commence.

As I said, we designed this to generate dialogue and debate, but we want to drive you to reach some consensus about key issues that may be actionable in the short term and also capture your ideas for long term. We are going to start with maintenance and dissemination next. We are going to go through what our breakout process will be and then turn you loose.

The NVCHS members have graciously agreed with their arms twisted to be the facilitator so that everybody has a chance to fully engage and not have to worry about keeping the business of the small group going.

They are going to ask for a reporter and a recorder. We would like a non-NCVHS member, if you will, to do the group report out.

We have provided for you a flip chart so you can do notes and visualize where you are going in the course of your own discussion and then we will be distributing a template. We need one report from each group with your

official report in. We will ask you to report out. That report out will be about three or four minutes, but we will see how we are doing on time.

The first question is around reaching consensus on near-term opportunities to improve maintenance of health terminology and vocabulary standards and deal with known operational issues. Kind of in the weeds. I think what we know from all of the appendices is that there are as many different approaches as there are systems. We are forcing you to kind of get to principles, principles that should guide maintenance and dissemination. Two to three short-term opportunities around maintenance, two to three short-term opportunities around dissemination, and principles that should guide how this works.

DR. ROMANO: (off mic)

MS. KLOSS: We will get to the right one.

DR. ROMANO: Our discussion topics. Three of them align with the areas in the environmental scan, but there is a fourth area in the environmental scan that is not to the discussion topic today, which is about content gaps. Do you want to mention what it is?

MS. KLOSS: I will. We are going to keep the group together for discussion of gaps tomorrow. Gaps come up first thing in the morning tomorrow and we are not going to

breakout. We thought we should by then all be working as a well-oiled machine.

This is what the template looks like. Maintenance and dissemination as you have scribbled out. But we only need one report per group. We have kind of encouraged you here to just begin by introducing the group storming stuff, but give yourself a little quiet time to organize your thoughts and then jump in.

With regard to breaks, we have our formal break scheduled for 11; however, if you – your group can negotiate that if you need to. You work it out.

(Breakout)

Agenda Item: Discussion 1 Report Out

MS. KLOSS: I think we will not go in numerical order. Let's start with Group 4. We will just go in the middle.

MS. LIPON: We kind of did the opposite. We used that to do our work and then we wrote on here.

MS. KLOSS: That is fine. We just need you to talk from the mike please.

MS. LIPON: With regards to the near opportunities to improve the maintenance of terminologies and vocabularies, we came up with a few items. The first one was we thought it would be useful to get some frequency or utilization data from large vendors and users to understand

which codes are actually being used a lot and be able to provide that information into the maintenance process.

We also talked about a stronger versioning system specifically in specific term backward capability. One of the discussions that happened around the table was that things change and then they break rules and there is not really strong process around that in the versioning to be able to deal with those potential breakages in the rules at the front end use of the terminology.

And the third thing was some type of stronger electronic quality control process with proper resourcing. That was our three with regards to maintenance.

Then with regards with dissemination, this is a bit of a pat on the back for NLM. The UMLS model is a model for others in terms of consistency of dissemination. It works pretty well they thought. And in particular, there were some particular standards that could learn from it, I think, is what we came up – particularly CMS was one of them.

Our second was some type of coordination of releases by domains or cross domains. So that you would understand a certain area and you would not have versioning or new stuff coming in that area a little bit at a time so that you would be able to better coordinate that.

And the third one was an interesting one and we have the same thing at SNOMED CT. The move to organizational licenses from NLM versus personal licenses. There was a big discussion around that. We had the same thing at SNOMED CT. It was an interesting discussion.

The guiding principles we came up with really – I am sure are going to be fairly consistent. Ease of use, quality dissemination, consistent, predictable and quick responsiveness to the end users.

And then we had one other insight and that was around the thought around a computable concept-based class definition that would be useful to users.

PARTICIPANT: Could you expand on that?

MS. LIPON: I am going to ask one of the other fellows to expand on that.

DR. CIMINO: The idea that classes would have explicit computable definitions as oppose to just a thing that is apparent of a bunch of other things, but actually there would be a concept-oriented approach to that.

MS. KLOSS: Thank you. Let’s go next then to Group 7.

MR. VREEMAN: We talked about a couple of different opportunities for improvement and maintenance. One of them was the idea of increasing visibility into the process. I think that goes throughout. It starts before,

anticipating what is coming, seeing ahead of time what is there and then also after the fact this idea of what changed and how. In general, the idea was improving the visibility across the board.

In addition, the idea of having extended comment periods for changes that are going to have significant or anticipated to have significant impacts and that is the idea sort of jumping ahead to maybe principle of fairness or openness but allowing adequate opportunity for input from the various stakeholders who might be concerned with or impacted by changes that occur.

And then the third opportunity for improvement is developing better techniques to ensure interoperability over time. It goes a little bit to changes that might alter meaning of concepts that might happen, but also in addition like how is it that organizations who track their consistent processes, their analytics, their patient reporting, and their aggregation with each version? How do we ensure that the data remains interoperable? That you can cross those versions longitudinally when we are thinking ahead to a 10-year, 20-year, 30-year, forever sort of look back period about a patient's health history. Those were our near-term opportunities for improving maintenance.

The guiding principles we thought of were this idea of balancing multiple perspectives so balancing the

direct needs of clinicians caring for patients and what they need and the changing evolution in science that happens. They need to be able to capture that information accurately with the operational impacts of reimbursements, getting paid, and changes that might affect those dynamics. So this idea of balancing those different perspectives was I think the principle that we were talking about.

And then the second principle was being directly informed by the needs of the community of practice for these different domains.

Near-term opportunities for improving dissemination. We talked about a couple of different things. One is having across the board for each terminology that we are thinking of sort of technical means of automating updates, meaning there is a separate question about when we should update and how often and so forth. Once that decision has been made, making the transition as easy as possible, but recognizing that that might mean multiple approaches for different kinds of users. That is, there might not be a single technical solution that works for every kind of user.

The second opportunity to improve dissemination was this idea of a routinized or a cadence schedule for disseminating updates and recognizing that that might not be the same schedule for each domain or each terminology,

but the fact that there is such a schedule sort of published helps people anticipate and plan resource allocation.

And then the third opportunity for improved dissemination. We talked sort of specifically about some of the opportunities and challenges harmonizing between ICD and DSM and other kinds of collaborative efforts and recognizing – this was kind of part of other insights to share was recognizing that these are difficult organizational harmonization challenges to get everybody synchronized or synchronized to the optimal degree when there are multiple terminologies with DSM, ICD and SNOMED, for example, others who are all making changes related to the same core set of ideas at the same time. That is very challenging, but would be an important way to improve dissemination.

MS. KOSS: Thank you very much. Let's jump over to Group 1.

DR. ROMANO: I think I will stand up so that I do not have to twist around to see people. In terms of near-term opportunities to improve maintenance, we spent most of our time really discussing the benefits of really establishing industry-wide principles for maintenance that would be adopted across all of the terminologies and the

organizations that sponsor those terminologies. I will switch over to discuss those principles.

The principles that we identified were first to have an open and transparent process for considering updates.

Second, to have systematic evaluation criteria that would be applied, criteria that would emphasize demonstrable clinical value that would include really clearly articulating the return on investment for a proposed change, recognizing the cost and benefits associated with updates. That was the second criteria. Systematic evaluation criteria.

The third was establishing a predictability roadmap with a specific cycle for updates and finally to recognize that the process of patient care must remain central. This whole enterprise is about collecting data that does not interfere with providing patient care and that actually ultimately improves our ability to provide care. Those were the four principles that we identified that could be incorporated into efforts to systematize maintenance across terminologies.

And then we also discussed about the need to prioritize messes that need to be cleaned up, if you will, to identify and develop a reusable process for taking advantage of public health emergencies to respond to those

emergencies with changes and terminologies that would cut across all of the various terminologies.

And then in the area of dissemination, I think actually we very much had some of the same topics that I think Group 7. We talked about the importance of a seamless process for disseminating updates that it should work silently with as little user intervention as possible, kind of the way our iPhone updates or iPad updates work.

We should look at the experience of other countries that may have better experience with dissemination including Canada, Australia, the UK and so forth. We should really bring vendors to the table and recognize the critical role of vendors in improving the user experience because they have a business case to do so.

Finally, we talked a little bit about the role of clearer usability standards potentially in improving dissemination.

MS. KLOSS: Have you captured those criteria on your report form? Great. Terrific. Let’s go to Group 2.

MR. ARGES: Many of the things that we heard from others over here are very similar to what we came up with. But predictability is a key component. The predictability process in terms of maintenance has to be well understood. Flow on a schedule and a timeline that is essential and that it also be aligned as part of the process.

The key thing here is making certain that maintenance, it kinds of goes up and down here, has a clarity around the process because there are boundary issues that we have noticed with respect to all the different terminologies that may be out there. A lot of overlap that exists. The question we need to answer is what is it used for, what and when to use it as part of that process.

There tends to be tribal behavior. It must be open and welcome to others. That should be part of that process to overcome the tribal behavior. Transparency in terms of understanding how the process works in terms of updates and changes so that new items can be introduced in terms of the maintenance.

There should be a government role in making certain that people understand what to do and when to do it. Oftentimes we use HIPAA today as the standard, but it only seems to have a narrow list of the code sets involved.

Finally, it should be international in scope. We want to be able to take advantage of the clinical knowledge that could be gained from having something that is international in scope to compare health outcomes and services, not only in the US, but elsewhere in the world. Did I miss anything from the group?

MS. KLOSS: Thank you very much. Let's go back here to five.

MR. HAMLIN: The two terms that came up in almost all of our discussions were end user and use case, that I think I have heard versions of that in a couple of the discussions. The first of our opportunities. We actually would like to change the name of maintenance to curation. We feel there is a much deeper involvement in a process for how terminologies are proposed and maintenance is what I do (indiscernible) three months. It does not really get to what happens within these terminologies.

That is relevant to our second point, which is really the communication of this curation process, the inputs, the validation process and the acceptance of these new concepts or the updates to the concepts that are done with the end user in mind. The information is all there, but to get to the dissemination, I think people really have to understand what is behind the production cycle and why these code – instead of the why and the how. And, again, from an end user perspective, an understandable, accessible way.

For our third it is again scheduling and version and control. What is the optimal schedule? Is there a place that can coordinate scheduling so that you do not have input overload from a multitude release in a single

timeframe, but also not forcing everyone to work on everybody else's schedules. There is some coordination that could happen there.

For our guiding principles, we really thought for dissemination, pushing this information through a common pathway, a resource center, much like the eCQI Resource Center, hosted by CMS. NLM would be perfect for this. Allowing a one-stop shop for information that can redirect people to very specific information, but again having a consumable, digestible amount of information at least at that one public facing point and you can dive as deep as you wish or you cannot. It gives you a whole host of resources. It is a very easy place to direct people to that does not require annual update of your membership.

And, again, as you disseminate out this information, think about that end user. If you want to get to the adoption, which I am sure we will talk about later, how can you direct them to the rationale for why they should be using these terms or these codes or these code systems in their practice or in their daily business and what is the business case for that whether it is a vendor, whether it is a provider or a hospital or so on.

MS. KLOSS: Thank you. Let’s go with six.

MS. KUEHN: Some of the same themes appear. When you get towards the end, things start to repeat. The word

transparency came out loud and strong that especially for all the public domain code sets. The process should look and feel a little bit more like the HCPCS process where you can see what is going on and should adapt some of the concepts of the notice of public rule making where you can see what is going on through the process. You can see public comments that come back.

All of that leads towards a holistic approach to what is needed to keep the code set current with the changes in medicine. Right now, just from the end user standpoint, you know there is a problem in the code set or there is a gap in the code set and you pray that someone has suggested a fix. But then you get to the point of dissemination and nobody fixed it.

We also talked about transparency so that we could make sure that we are attempting to observe the boundaries of the code set so it does not morph into something that the code set was not intended to be.

Then with the dissemination, we said predictable schedule like others have said and then matching that schedule to what the driver is for the need for the update. We recognize that all the code sets are different. SNOMED has a different requirement for the need for maybe faster updates versus all of the code sets that are driven by reimbursement time periods.

We focus some on easy to understand changes, adds, and deletes. Kudos to CPT where it is built right into the next generation when it is put out versus some of the ICD set where it is difficult to tell what has changed. There is no red line version built into it. There should be a basic minimum standard to be able to tell at any given point what has added, changed, or deleted.

This sort of boiled down to principles that knowing that all code sets are different. There is much variability in what we are doing. We need to focus on go electronic. That would be recognizing that different electronic might mean different things to different codes sets. The PCS hyperlinked PDF file is exceptional for that. However, a paper or a static PDF is not really optimal because it does not help us move forward to thinking in the ICD-11 world.

Then the format of the delivery should be easily consumable by the end user, easy to get at, easy defined. And that elimination of cost barriers as much as possible so this is a little bit of a repeat.

MS. KLOSS: Thank you so much. Group 3.

MS. LEON-CHISEN: I am going to start out with the other insights to share so starting from the bottom because this kept coming back multiple times that we need to use a wider lens, focus on a broader set, and there are many

other code sets that are not even mentioned on this paper and that are evolving even as we speak where there are millions of codes. The biggest example is what is happening in genetics. Those are not addressed here. I think social determinants of health were another example that was brought up.

And then the other important key was who is going to pay for all of this. There was a concern about that it is important to identify funding. That kind of shaded some of the other recommendations that we had.

For the near-term opportunities for improvement, one was developing some sort of a catalog, information about each code set, not just those that are identified in the paper and needing to distinguish between creating new content like a new code set, a new way of naming things versus improving or expanding on what we already have today so that there is a different process whether you call it maintenance or updating versus just trying to invent something totally new.

There is a need to provide clear information to the community on what are all these code sets and how do you ask for changes. I think for those of us in the room we probably know how to do that, but to the general public, it may not be that easy to identify.

Some guiding principles would be that there would be a public-private collaboration both for the maintenance and dissemination. The public being where individuals could make recommendations, review things, do things on their own, and the private part is where the money comes in. This is where we were talking about groups like Google and Apple, developing an interest in health care and what does that mean when they bring lots of money to the process.

The word pragmatic kept coming back also where we need to have a pragmatic approach. Keeping an eye on the end user's needs, but also keeping an eye on the content of our requirements, knowing that you cannot – if you want to have an effective system that you are going to have some structure and that the content developer may have specific deadlines in order to meet whatever they need to do for their internal process.

Another principle I think similar to what others have said is there should be less duplication, ease of integration, ease of use. And one thing we came up with also perhaps having a chief coordinator, some organization or association or you name it that would perhaps try to coordinate all the different code sets and try to come up with some coordinated release dates, release formats although we sort of divided on what that coordination should look like and how much there should be.

As far as key characteristics of successful dissemination, just like we had a chief coordinator, there would be a chief education, but we limited that by saying that it would be system. That we thought it would be too difficult to have a chief educator for every single system in one place.

There should be support in reinforcement from federal government where there could be guidance, but there would not be a reliance on them necessarily to drive the process, but maybe to just make sure that things happen.

We talked about timely native formatting where the changes are delivered in the exact same format that is being developed versus some sort of combined formatting. We talked about UMLS and the good work that they do. I think we got all the main points. Did I miss anything here?

MS. KLOSS: Good jobs. We got a lot done in an hour and a half. Don't you think? Are you game to just keep rolling? And then the reward is lunch.

We are going to do the report out of our second discussion after lunch. When you finish your work, which will be the same drill we have just been through, but with the topic this time of adoption and implementation.

I think to the comment about maintenance versus curation, we struggled a little bit in the environmental scan as you noted about what do we call this. We have a

formal regulatory adoption process that plays in this space. It is multiple steps, determination of whether the rule, proposed rule, everything we went through in ICD-10.

As we were pulling the scan together, we realized that we do not seem to go through that process for the other name standards. It is ICD because the version is specifically named in the regulation, but CPT does an annual update and you do not have to go through a regulatory process to get it adopted. That was kind of an interesting aha I guess for me. It is so obvious. I hadn't really thought about it in the context.

What we are asking you to look at here is adoption and implementation. What we mean from adoption is how do we move the name standard along to the point where the end user knows they need to put it in place. It is not only through regulation because we have seen some new levers as you read in the environmental scan impact adoption. SNOMED through Meaningful Use requirements. When we say adoption, we are not only talking about a formal regulatory route. There are other levers certainly that are in place. The USCDI and other approaches.

And then implementation is really kind of the best opportunities, the best practices for what those in the end user role should be thinking about in terms of moving forward.

Reach consensus on two to three near-term opportunities to improve the regulatory process and we mean that in the broader sense for terminology and vocabulary standard adoption. And then the characteristics of organizations that successfully implement and use vocabulary and terminology standards. We know there is a vast range from those that have vocabulary servers and have vocabulary specialists in their organizations to those that go out and buy a code book. That is the real world. We are trying to tease out some high-level thoughts as to what these capabilities should be going forward and then again principles.

DR. MCDONALD: Do we have to address the full regulatory thing, which I think is not a good – I do not think you are going to get there that way.

MS. KLOSS: We do not need to address the regulatory process. It is what it is.

DR. STEAD: We can think about given what the regulatory process to what degree should it or should it not be used for terminology and vocabulary standards because one of the things that – I think Linda said this, but I will just put a point on it. We really worked through the environmental scan. It became clear that, if you will, the sub-regulatory guidance that in many ways the USCDI is and so forth is another lever for getting things into a

predictable cadence. CMS' payment rules are another lever. And the regulatory process is another lever.

We sort of ended up as we came out of the environmental scan seeing those three levers as existing ways that could drive adoption. We are clearly distinguishing between adoption which means it is something you are supposed to do and implementation, which I used to call adoption by the industry, but I have now had that scrubbed out of my colleagues on NCVHS.

MS. KLOSS: Any other questions? We will go until about 12:25 and then break for lunch and then we will be reporting out when we return.

(Breakout and Lunch)

AFTERNOON SESSION

Agenda Item: Discussion 2 Report Out

MS. KLOSS: We have got just 30 minutes to do a report out on Group 3 and then Kathleen Morris is from the Canadian Institute for Health Information is going to speak to us. And then we are going to tackle the subject of coordination and governance, which will be a mid-afternoon wakeup. But we really are appreciative of how much great input we have received already and really looking for to these report outs on adoption and implementation. Let's start with Group 3.

DR. MCDONALD: Near-term opportunities to improve regulatory adoption. We need to avoid using name versions of vocabularies to avoid the ICD-10 problem where it got into a deep structural turmoil. In fact, I cannot describe it accurately, but the current rules for most of the other vocabularies do allow this transition from version to version. We should probably imitate that. We do support the use of rulemaking, not the way I see 10 was done, for some cases or maybe many cases as well as such as USCDI, ISA, and guidance of various kinds so the sub-regulatory rulemaking.

The one I had the worst trouble with was the second one. Key characteristics of successful implementation and use of T/V by stakeholders. And of

course, it said something different on the screen and I could not figure out what the object of the description was. We winged it. But with the help of my team here, we got some content. We need to learn who is using what to figure out who is doing it well. That was the first thing.

And then we think that the larger organizations generally do better than the smaller. They have deeper resources and they can actually do the work needed to build them and put them together. And just as a case study, we have noticed and my group supported me saying this. The big commercial labs all use LOINC. You can download on the website. Little hospitals do not very much use LOINC.

I came across the fact through some insurance companies, I think mostly it happened because the insurance payers insisted on it so that they could collect this data. I know they do collect the data and the hospitals do not have the same incentives. Incentives are important. That is speculative whether that is the mechanism by which that happens.

And then what guiding principles should guide adoption and implementation decision making in execution. Do it right. That is not what they said. I do not think we covered ourselves on this one, but maybe we did. Decision making differs by the kind of lens you are looking through. One size does not fit all. That is a dodge, but there are a

lot of ways to do it. Adoption must keep pace with the changes in both medicine and billing and financial commercial things.

There was an insight was that we should be aware and I think everyone here is that the standardization and the signing off on vocabulary standards cannot be the same as, for example, message standards. Meticulous thing. Everybody gets a vote. You pick this. You pick that. But if you have 2000 or 3000 terms coming in a year from ten different organizations, it has to be smoother and easier than that. There has to be some pass off to the leadership and the experts who were working at it and then maybe with some possibility for entering into the process. That is all we got.

MS. KLOSS: Very good. Let’s go to 5.

MS. SKURKA: It is good to go early because then others just repeat what you said sometimes. Improving regulatory adoption. We said make it aversion update and not a regulatory change with manageable scope. That was in our readings, but that would certainly be important.

We recommend articulating a business case and benefit, arguing it as a business case, stressing the why of we adopt because we are always busy. Again, we talked a lot about our failures in I-10 and the number of issues that we had.

We feel we could always do a better job of stressing why we want to do this, not just what we are going to do.

And as much as possible and it works better with some systems than the others, incremental changes. We talked about incentives also. We do not know how that works, but that word kept coming up.

What guiding principles? Again, we said maybe a way is if you can get a third. We talked about dealing it with the roll out in thirds. If you can get a third of the users to want to get behind it and be very supportive of it, pretty soon you are dealing then just with a middle third and eventually those in the final bucket will come along. You eat the elephant in bites.

The key characteristics of successful implementation and use. We need improved decision support systems. We need support for the tools and decisions and it is grounded in a knowledge base. We brought up patient safety. We talk about data all the time, but a big part of all of this data we collect is can it be used to improve patient safety and outcomes because that is at the end of the day what we all want to do.

Some guiding principles. Again, we said do it in some kind of an incentive process with the first third, the middle third and then the stragglers. And then we said the

kiss philosophy, keep it simple stupid. If you Google the words administrative simplification, maybe we want to rethink those terms. With HIPAA and everything, we really did not have a lot of administrative simplification. We do not want to call it that.

And then finally, other insights. We talked about identifying the benefits in any new revision of a system. I-11 was a famous example. Why? Why do I need to do this? How does it benefit me? In terms of consumerism, tie that into a competitive advantage and into our tracking and utilization from a competitive advantage also.

MS. KLOSS: Should we come over here to Group 1?

DR. NARCISSI: For our near-term opportunities to improve regulatory adoption, we thought there needs to be a more realistic assessment of cost using real-world scenarios. Also, vendors demonstrate adherence of schedule of adoption to – and also get involved with certification so that customers can use the new implementation, some type of usability standards.

Also, we talked about automated and coding and that there are some new tools I guess that are available for the ICD-11 and that is out and perhaps that needs to go across all the terminologies and vocabularies.

What guidelines and principles shared accountabilities between the vendors and users in agreeing

to adopt and have successful adoption? And be explicit about cost. We did a lot of talk about the cost of changing and moving forward with a whole new version or just even the cost of changes to a few codes from year to year.

There needs to be attention to the readiness of the users to adopt. As I mentioned before, there needs to be some type of implementation and mapping tools.

For the key characteristics, we feel that it would be successful if the updates require little and user attention so that it would really be seamless for the adoptions. We need criteria for defining successful implementation.

And some of the other insights that we talked about were outcomes based at even some of the other countries are looking at their health care system really based on outcomes. I know we are doing that somewhat here and that is kind of all tied back to their coding. And also nationally developed and vetted implementation standards should probably be developed on how to adopt and implement.

We also talked about some kind of a warranty approach like your car so the end users will know that when – they will know that they are using the most up to date versions of the coding systems.

And then the other thing that we talked a little bit about is that the vendors need to be at the table

whether it is in a scenario like this or in the development of the code sets so that they can take it toward implementation.

MS. KLOSS: Very good. Shall we go with Group 7?

MS. MORRIS: We have lots of similarities that we have heard from some of the other groups. I will try to pick out the ones that are different.

One suggested maybe a different spin on what we have heard around this idea that the standard can evolve and not to force it too much into regulation is the idea that there needs to be balance between the compliance benefits of regulation and the flexibility for the version of a standard, for example, to evolve.

We talked about having the least complex regulations so fit for purpose. There was a suggestion that it would be really great to get some best practices for non-regulatory adoption and what other levers are there in terms of getting adoption and –

Guiding principles. Like many others here, we talked about being clear about the expected outcome and focusing on the why rather than the mechanics of the how and engaging a wide range of stakeholders, vendors, and clinicians. There was a very long list.

In terms of some characteristics of some successful implementers, some of this is just having a

basic understanding and appreciation of terminologies and vocabularies. And, again, just sort of building on the last speaker. The idea that you would use those for multiple purposes that there is a compliance piece that may be tied to funding. But there are also quality indicators or safety indicators or so many other benefits that could accrue from having this and the ability to benchmark.

Having formal clinical leadership and support. Very explicit in terms of the adoption.

We also talked about size and scale. Standards maturity model. I think it is just recognizing that standards are at various stages of maturity and at which point is the sweet spot for getting things into regulation.

MS. KLOSS: Very good. Let’s hear from 4.

DR. BROWN: I think a lot of our themes really overlap with what I have heard from some of the other groups in terms of near-term opportunities. We did not really focus on regulatory so much as administrative kinds of things. The first thing we thought was that streamlined administrative processes for versions need to happen and no reason not to do that.

That there needed to be clear understanding and communication of the value proposition rather than try to make the lightbulb want to change. It is awareness of the value rather than being afraid of the stick.

We used administrative simplification also with the same kind of sense. But if there were, for example, better mapping from terminology that was being implemented, the obvious example being ICD-10 to SNOMED. If that had gone out, that would reduce burdens immensely and made it easier to comply so it is lowering the energy of activation as well as tight integration between existing terminologies that may rely on each other. Those are the short-term adoption instances.

Key characteristics. Organizations where there was support including leadership support, clinical champions, a willingness to invest in training and funded in implementation.

Another cluster of things was around having centralized terminology services of people who were responsible and groups who were responsible for the maintenance uptake, curation and the like. And also it was part of the curation that locally there was a strong editorial process and some skill sets available to keep goodness happening and silliness from mushrooming and becoming incorporated. That is a formal term.

Guiding principles. In general, we thought that it is important that there is some actual value provided to the organization and that value clearer and brought into. That may be making some processes easier and may be improve

care. But it has to be things that the organization itself can understand and can relate to as an organization.

We thought that there should be – high-quality terminologies should be those that are preferred and supported. I will not invoke the Desiderata, but concept oriented, concept permanence, recognize redundancy.

I also thought we could learn from other industries. Terminology is a semi-cottage industry, but there are lessons to be learned from software engineering environments as well as life critical, patient safety practices that we do not have any idea about.

And then finally, as a principle, we thought that whenever a high-quality terminology was fit for purpose and maintainable, that they should be used natively so as to eliminate mapping, which is expensive.

MS. KLOSS: Thank you very much. Again, work is getting a wealth of insights. Let’s go with 6.

MR. MOSCOVITCH: Thanks. A lot of what was said we also talked about. There are few levers within ONC to make progress. First is the USCDI. As ONC adds additional data elements to the USCDI where possible, the agency could indicate which vocabularies to be using or terminologies to be using.

Same thing with APIs. ONC is going to be issuing regulations on open APIs in the fall and Congress said that

those need to ensure the accessibility of all data elements in the EHR. In implementing those regulations, are there certain standards or terminologies that could be identified in those regulations?

Similarly Congress required ONC to develop a series of measures to evaluate interoperability among other things. Among those measures could the use of different terminologies be embedded into those measures that are created?

We also talked about some non-regulatory approaches with the markets, specifically the Argonaut Project, which has identifies a series of vocabularies to use for different data elements and their exchange. Apple has adopted those to get your health records on your iPhone if you have one. Similar market approaches to identify different terminologies and use different terminologies could also encourage adoption.

In terms of the characteristics, really three came out. One is they need to be a level of independence. Two is there needs to be some kind of bully pulpit in order to encourage adoption and implementation. Three, there needs to be some mechanism for funding and staffing so that it is sustainable.

In terms of principles, we talked a bit about approaches that are used abroad with quality assurance and

auditing that standards are used and used effectively. There might be some analogue that could be approached here in the state.

Two, that the data need to be accessible so regardless of which terminologies are used. You first need to have access to the data.

And third, just to be cognizant of the burden on clinicians and that the benefits attained from using the different terminologies surpasses any burden of using them.

MS. KLOSS: Thank you. Group 2 is going to bring it home.

MR. MCLAUGHLIN: I do not have anything to show. We did not write anything down there. A lot of this has already been said obviously by all the other groups, but the idea of balancing flexibility, some minimizing optionality. I think this is unique to our group, the idea that you do not allow for any version of any code system to be used. You limit that down to specific – you pick a terminology or vocabulary for a specific domain and do not allow for three different options there. But then you do not lock in a specific version. There has to be some balance between locking in a version and allowing for any version of a code system to be used.

And then another thing we came up with is a clearly articulated strategic vision for moving forward

sort of starting with this environmental scan that has been done and looking at the purpose and scope and the pros and cons of each of the vocabularies and terminologies that have been listed in this thing and going forward from there and along the way having stakeholder engagement, having vendors involved in this process to move this thing forward and really get a plan for moving forward and how we can build off of that.

For key characteristics of successful implementation, we said leadership and commitment from the top for the implementation and use of standards. And then recognition of the value of information-based decision making so not just collecting information for the purpose of collecting information or for external incentives, but what is the value for the organization in making decisions.

Guiding principles. Avoid burdening the care providers with documentation and information gathering. This has been said, but identifying and aligning values and incentives with the implementation of standards for the organization.

And then an insight we wish to share. This is sort of pie in the sky, but if we could make this work, probably a lot of other things would fall into place, but aligning health care incentives with patient outcomes. Not really in the scope of this group, but why not?

MS. KLOSS: Any question or discussion? Is this a little harder to grasp just because of the adoption angle of it? We probably just did not have time to delve into what it takes to be good vocabulary-based end user organizations. I think you have really given us a lot of direction and thinking here.

Bill, do you have anything?

DR. STEAD: Fresh thoughts from my perch are the idea of usability for patient-centered CDS as an evaluation criterion. I should have thought of that, but I had not.

I like this idea of trying to figure out the balance between optionality and flexibility. I think we are beginning to get at some things that could help us with useful guideposts. Thank you.

MS. KLOSS: Let’s just roll right along. Our next agenda is to hear from Kathleen Morris, who is vice president of Research and Analysis at the Canadian Institute for Health Information. She was a little late arriving today because of a canceled flight from Toronto last evening. We are delighted to have CIHI here.

And our reason for extending the invitation to our friends from Canada is just the points that you have raised several times today already. Perhaps there are other ways to do things. We need to look outside the US for ideas and models and CIHI has a long-standing relationship to

what we do at NCHS and through our North American approach to these.

She is organized her talk so we will have plenty of time for discussion. I hope we will have some discussion – after her formal comments.

Agenda Item: Learning from Other National Health T/V Models

MS. MORRIS: I am just going to stall for a second while I get the clicker, but thank you for having me. I think it is an inspiring time to have a conversation like this because health information from my perspective has changed dramatically in the last decade. It has gone from an administrative chore to one of society's most valuable public goods. It is used for management and policy and research and care and it really is the basis of better and more equitable outcomes. I think that is a pretty inspiring place to start.

It is also great to see a much greater respect to standards in general, but also very specifically to terminologies and vocabularies in terms of aiding and abetting that. I think that is wonderful.

I do work at the Canadian Institute for Health Information. I will just give a quick disclaimer. I head up a group of about 150 people. Most of those are people who try and make sense of the data when it comes in and try and

turn it into greater indicators on terms of efficiency or quality or safety and demonstrate the value of using this. But we do have about close to 30 people who work in a standards function mostly around ICD and the Canadian classification system, which is called interestingly enough the Canadian Classification of Interventions, CCI.

But we also have a whole lot of other standards that are managed throughout the organization. That gives us a unique perch in terms of being able to talk about things.

Just before we start, the Canadian Institute for Health Information is quite a mouthful. We always call it CIHI. It is just a friendly kind of CIHI from Canada. Easy to remember.

Just a few very quick things about Canada. I think it is a critical context in terms of where we go because I think what you will find is our contexts are pretty different. That said, there are things that we might do well and there is probably a lot of things that we have done that you want to avoid. Hopefully, we will give you insight on all of those fronts.

Just to give you a sense, we are like a tenth of the population of the US, mostly urban contrary to the myth of the great vast unsettled areas. We are mostly along the US border.

A couple of things to think about and this is important in terms of language and how people view the concept of health that we have 5 percent of the population that is indigenous. I think with the current government particularly playing a much more assertive and prominent role in terms of how they frame health concepts and how they manage information.

We are quite ethnically diverse. But it is interesting to note that 20 to 25 percent are first language French so also an important piece for us when we think about terminologies. It is probably not a factor as much here.

And then we have a federal system. There is a central government, ten provinces, three Northern territories, huge difference in populations. They all kind of have a similar vote at some of the consensus meetings that we have. One province has 14 million people and there are two territories that are south of 35,000 people. It is just gives you a little bit of context for where we are.

I am going to start just quickly talking about the division of responsibility in Canada in terms of the various levels of government. We will get in after that too some of the things that the organizers are really interested – highlighted for me, talking about just the collaboration that we have between the different levels of

government and why CIHI exists outside of government, which we do.

A little bit about where we are today. Our own experience about 15 years ago ruling out ICD-10. A little bit around ICD and LOINC, SNOMED, and our views on the National Coordinating Center.

The federal government has direct service responsibility for a very small number of Canadians in terms of health care. They have armed forces, some veterans, federal inmates and many indigenous people. I would say that that particular point is our points of friction because while they cover a small number of people, many of them have not great health status. The services typically do not make their way up to public reporting of performance or quality or safety. That is just a little wrinkle that causes lots of consternation.

Their biggest job is to provide some money for the provinces and territories. A lot of that is regular transfer payments that go, but also they have some policy levers where they want to drive action. For example, they have just sent $11 billion over ten years to improve access to mental health and addiction services and community care. They have that financial lever to drive action in certain areas.

One of our jobs at CIHI – in exchange for that money, typically what they would require is public reporting. One of my recent jobs was to broker the set of indicators, which ones would be the ones chosen to measure that compliance with the funding contribution and then we will work on the definition and reporting of those over time. That will probably result in some new data collection. It is not really regulatory compliance. But in order to get the money, you have to generate – you have to send us the data so we can put out the indicators. That is kind of how things get done often in Canada.

The real work in terms of the actual delivery of care rests with the provinces and territories. Each runs their own health insurance plan. Everyone has common coverage for physician services and for hospitals as long as the services are medically necessary and there is no definition of medically necessary. They are a little different from one place to another. They have a few other responsibilities.

I think one of the biggest pieces though is that they are not required to submit any data anywhere. But we have tons and tons of data from across the country. The only way we are able to obtain that is through moral suasion, ability to deliver value so benchmarking environments or value added. CIHI calculates the equivalent

of the DRGs. We provide case mix, value add, benchmarking, lots of capacity building and support. All of the data flows involuntary and the compliance with standards is – for us to receive data, we say you need to adhere to the standards. But their decision to send it to us is completely voluntary.

I guess another point to just mention is that health care is a huge preoccupation of all of the provinces and territories largely because it is taking up about 50 percent of their budget right now. There is lots of attention paid to it.

There are three kind of – well, there are four, but we will talk about the first three pan-Canadian organizations that have data. One of them is called Statistics Canada. That is the organization that runs the Census. They do a bunch of other survey work. They typically have mandatory compliance with some of their surveys. That data is interesting. It has a lot of population health data and it is linkable with our data.

One of the things I read in the environmental scan was around having social determinants of health information. We do not collect that directly, but we can get that through linkage in most cases.

We also work with Statistics Canada. We come up with how we would use equity. We call them stratifiers, but

equity definitions in health. Some of those would be around geography or income or others would be around – they are more complicated right now around gender and how we define that. We would run the consensus workshops on that and then Statistics Canada would survey using those definitions.

The middle group is the Public Health Agency of Canada and Health Canada. Those are more formally part of the government, very centrally government. They have a relatively small role, but they are in there. And then the Canadian Institute for Health Information has a whole lot of voluntarily submitted data on health services, on health professionals, and on health spending.

Lots of gaps. Some of those are interesting in terms of the discussions that we have been having here today. We do not have great primary health care information. We have physician billing data, which is comprehensive, but we do not have a lot more than that in a standardized usable way.

We do not have a lot of information on private providers like dentists or psychologists or some mental health services that are in the community. And the social service side or the community-based services side is also pretty weak.

The question was how did CIHI end up as a nongovernmental organization. This was kind of fun for us

to actually work backwards and figure out. We are 25 years old next year. We are still relatively young. But we came about from two organizations that were part of government, Stats Canada and Health Canada, and two nongovernmental organizations. One was largely an Ontario-based organization that did discharge abstracts from hospitals and case mix that really for one province and kind of had an eye on expanding. And the other was a group that has all of the essentially the chart of accounts for Canada.

It is hard to create a successful merger if you have nongovernmental organizations who do not want to get into government. I think it had to be housed outside of government is probably the short answer.

But it kind of had a funny beginning because they had this fellow who was actually a senior executive at AT&T in the US, but came back to retiring in Canada. His last job was to be the chief statistician of the country. He was asked to take a look at health information across the country. He had a good way with language. His word is – it was in a deplorable state. Deplorable state was not so good. He had another good line about it was an unmapped forest with no boundaries.

In any case, his poetry aside, his end result was to create an institute for health information and that is where CIHI was born. From the organizations that founded

it, the financial standards one and the Hospital Medical Records Institute. Those were doing well. People were looking for them to expand. Those were efficiently run.

And a quote I found from the newspaper around Statistics Canada at the time was it was a flailing bureaucracy with low morale and in desperate need of a shakeup. I think that may be another reason that we ended up outside of government.

To just set the record clear, I think Statistics Canada is probably a world-leading organization right now. It is fantastic. But it clearly had a little valley at the time the report was written.

Just a few quick facts on CIHI today. We are independent. We are not for profit. We have about 100 million Canadians, which is probably 75 million US annual budget. Most interesting thing is that we are funded by all levels of government. We have the federal government. Every single province and territory pays money into it. You could look at it almost as a co-op. A lot of people who use the data pay into it. It is a very different kind of model.

We also sell some stuff, but I would say that that is a small percentage of our revenue. A lot of the things that we actually charge people for are more of a cost recovery kind of basis.

We work very hard to maintain our non-governmental framing because I think that that does us very well. I would say a tense kind of political environment between a federal government and the provincial territorial governments – there have been very organizations that have survived for as long as CIHI. I think some of that is because we just sit in the middle and we address the facts. We put in a lot of analysis. We typically do not make recommendations on our analysis, which also helps.

I think that the – our whole ethos is better data, better decisions and healthier Canadians. Lines of work we have is we have standards. We have all kinds of standards. Not all of them are terminologies and vocabularies. We have a bunch of them. We are the Canadian arm of the ICD and do work through the WHO-FIC. We also have the financial chart of accounts.

We are the Canadian arm for a lot of data submission standards. We have interRAI, which are standardized client assessment. I noticed in the environmental scan again around some gaps that you folks talked about with respect to function or cognitive ability so the interRAI set, which is used in almost all of our nursing home or residential care facilities, our long-term home care patients, some mental health. They all have a common process or a common standard for assessments.

Because we collect so much data, we have a lot of standards that are connected to hospital data, but may not be ICD. For example, we will define what an observation unit in an emergency department or we will define what an ICU is for the purposes of data collection.

We also have, which I think is very important in our role is privacy and security standards. We receive all identifiable data that can be linked and combined across the entire country. It is very good to follow a patient through time.

You can just see here just a very wide range of data. What we do with that and I think this is sort of the value proposition that we offer people is we can give them things on access, on quality. There are lots of private, reporting tools or BI tools where people can dig right in. There are analytical reports. There are lots that they get from it.

Again, we have separate relationships on the privacy and confidentiality side. One of the things that we do on behalf of all provinces is fill any researcher data requests for them and making sure that we have some process or criteria for coming to agreement about what is in the public good and who gets record-level data versus who gets aggregate data cuts.

One question that we were asked is about our trip on the ICD-10 route. You are going to have to remember that this is quite old. We did this over 15 years ago. The context is completely different. Lots of providers at that time did not even have access to the Internet. I am going to go through this reasonably quickly because I think some of this may not apply very much.

Lots of dates on this, but the main point is from the time we thought about wanting to do ICD-10 to the time that we were ready to implement, it took ten years. Then the next slide will show you that it took five years to actually get it done once we said we were ready to go.

Some of the complexities here. It took five years. Each province implemented at a different time. If a province implements I-10, they went for the full deal. It was not a choice hospital, Y hospital or organization. And at the time, it was fundamentally hospitals. But it was not really a choice. Your province went all at once.

Only four of them made the initial 2001 deadline. And the last one is Quebec in 2006. Some of that was related to the French translation issues and having those ready on time.

This was a very difficult transition for the kind of work we do, which is often providing that value add because it is very hard to have comparable information when

people are on different versions. I am sure you are experiencing this now, but the crosswalk from I-9 to I-10 is ugly. We did the same with the – I think for us the intervention side of things was even a bigger departure. It was not a one-to-one mapping. It was one to many or many to one. It was very difficult to make sense of the data.

I think one of the areas that we underestimated things the most was on the case mix side and how difficult it was to readjust the grouper. In fact, we have a comedian in Canada called Red Green, but we called this report our Red Green report, which was the – it was very red, but it was which DRGs or CMGs could you still use.

Three things I guess to tell you very quickly about. One of them was around training. We did a lot of training. We did a lot of that in person. This was for health information professionals. I think we do that very differently today obviously, but we did this in person mostly.

If you can remember at the time, people had coding books. Now, there are no coding books. People are all pretty much electronic. We changed our training to include like a half-day course in basic computer skills because it was really a very different world that we were living in then.

And the only silver lining to this staggered implementation was that we could adjust our training as we went.

Lots of talk about the business case and making sure that the costs and benefits are clearly outlined. I think everybody underestimated the cost of fully moving to I-10. That would be the provinces, the hospitals, us, the vendors, for sure. It took longer and cost more.

We just talked about – the data also got terrible for a little while in terms of the use of the data because it was not comparable. It was a tough transition.

The good news is the information quality held up pretty well though. We did re-abstraction studies to see whether things were working well and they did. The kinds of information we needed for risk adjustment was still there. People slowed down a whole lot in terms of their coding for the first six months, but after six months, they were back up to normal, which actually I think might have surprised us. The last bullet point. You can tell it is in three times so it was very difficult for us. We just had a hard time trying to maintain our value add part of our business.

I am just going to flip to the other piece because I was picking up a bunch of things as we were talking. Where we are today with ICD-10 is we actually work on a three-year change cycle. We put out changes every

three years. We have a very consultative approach for people to feed in ideas. We get our ideas from a number of sources. We get them from our own staff because we do a whole lot of analytical work with the coding. We can identify where the gaps are, the imprecisions are. We hear from researchers.

We run what we call an e-query program. If coders are having challenges or trouble or are not sure how to code certain things, how we respond to those. If we get enough queries then we probably need to either change the code or clarify the standard. It is often clarifying the standard.

We actually have a dash CA. We have ICD-10 with a Canadian version. We have little flexibility because of that in terms of the changes. I know as the World Health Organization is considering ICD-11 that that is something that they are strongly discouraging. I do not know if we sold everyone in Canada on that yet.

The other piece that was interesting is that there is always an evolution document any time the codes change so that you can follow the transition from one to the other. We have two bodies that we meet with probably at least semi-annual and some of them quarterly.

One of them is the provisional and territorial CIOs, chief information officers. That is an important

piece in terms of understanding the capacity for a system change. We obviously work with the vendor communities as well. Hearing from the government reps is important.

We also have semi-annual content meetings with people. There are a wide range of issues that can come up, but those are consensus building in terms of determining priority of changes and magnitude of changes that can be absorbed.

The other interesting piece is there is – at the beginning of the talk, I went through a few national organizations. There was Stats Canada, the public health agency, us. There is also an organization called Canada Health Infoway. They were created in 2000 and their main job was to accelerate progress on the interoperability of health records.

It is interesting. They have done that mainly through money. They are federally funded. Typically, they supply matching funding to invest in electronic health records and one of the stipulations for that investment is that you embed standards. They have spent a lot of money, for example, embedding lab systems, but would have LOINC as the standard of them. Their carrot has been money for standards.

I do not know if it has actually honestly worked all that well truthfully. Interestingly, organizations kind

of moved away from the interoperability mandate even though I would say we are a long way from fully having that and they have shifted to a new strategy where they are going to develop products. They are going to have PrescribeIT, which is sort of an e-prescribing product. They are going to have something called Access, which is essentially a patient portal although there are lot of competing patient portals. It is hard to know where they are going with that.

One of the things that is going on right now too is there a review of some of the health-related organizations in Canada. There may be some decisions on that is full, but I think there is a strong inclination to bring what they call digital health data organizations together, which may mean that some of the standards work that happens today in Canada Health InfoWay will come back.

One of the standards that InfoWay maintains as SNOMED – that is really interesting. We have a hard time first of all hiring people who know a lot about SNOMED and who also understand other terminologies and vocabularies. I know that is the challenge.

A lot of the work that we have been doing is trying to crosswalk things. We have worked, for example, with the Canadian Association of Emergency Physicians, trying to come up with a good SNOMED ICD-10 intervention classification. We have that and it is pretty well adopted.

They have 100 top emergency department interventions. I think they have 800 diagnosis codes that they use.

I think it could work better. I am very interested while I am here in learning a little bit more about IMO and some of the other mapping groups that you have here in the US.

The other thing that we have been doing is working with the World Health Organization on an I-11 SNOMED kind of piece. Initially, the idea was that those two would be easily aligned. I think now it is still mapping. And the initial mapping work was not all – the concordance was not that great. That was kind of paused in December of 2017. Ideally, we will get back to that because I think agreeing to disagree and just kind of having the two separate does not really seem like a good solution to us.

The next piece just to talk about a bit is CIHI and the WHO-FIC Network. I will talk a bit about what we do there. We are actually quite active through the North American Collaborating Center. Statistics Canada is in there because they have the vital statistics so they use ICD for mortality data.

But we are very actively engaged in committees and reference groups. Some of that has been up until June, updating ICD-10, working on ICD-11. We, like in the US, do

not have super widespread use of ICF, the International Classification of Function. I laughed when I read the environmental scan note. It was lots of interest and not that much uptake. That is exactly where we are at.

Development and testing of ICHI, which is my favorite acronym. ICHI, as I understand it, is reasonably similar to what we have as our Canadian Classification of Interventions. If we go ICHI, it will not be that much of a departure I am told. There are lots that we are engaged in there. In fact, one of our biggest brain drains is sending some of our best people to the World Health Organization and who never come back.

I guess the other piece of this is kind of interesting is that we for many years have been engaged with the US as part of the North American Center. And what we are seeing now is that there is more of a push to have country-specific collaborating centers. I think that that is something that we are pondering at the moment about whether the arrangement still makes lots of sense. And some of that is just around – we used to be relatively close on versions of the ICD. I think 10 was – we were quite far apart. 11, we are not sure. Some of the things that we discussed a bit earlier in terms of the French language translation are a ginormous piece for us. That is one that we might partner with other people on. And we actually do

some work with France, in fact, on that even though the French is quite different. It is a big leg up.

Mexico has its own center. Why don't we – I think that we have had a great, very collaborative, very happy relationship working with the US on this, but it is just whether it is time for us to think about being our own center.

One of the – it is not an obstacle. One of the things we cannot do as being part of the North American Center is be a lead of a committee at the World Health Organization or a chair or what the correct word for that is. I do not think that that has actually caused a lot of angst, but there have been a few times just in the last year or so where people have been asked to chair committees that they could not do. That is just something that we are noodling on now.

I do not think it would change at all the cooperation collaboration that we have had with the US would still take place.

Tell you just a few things about where CIHI is. We are spending lots of our energy trying to modernize data supplies. That is making – we have heard lots of discussion about this today. It is just making it really easy at the front end to get data in, which will make it more timely,

which will just be a little less burden in terms of getting the data in.

We have this kind of a model about how we report out so a lot of our work is around public reporting. There is an accountability function to that. But there is also quite a lot of just provision of data to people who want to use it, which we are very big on. Many of those people are outside of health now. Lots of interest from economic development and genomics and AI and NL kind of organizations who want to use health data because there is such a long history of really standardized data. The trick is trying to figure out what is in the public good and public interest there. And then we have a BI center.

A lot our hospital or nursing home organizations might be relatively small. If they do not have their own BI system, we have something that works pretty well for them.

We are shifting to digital reports and then – we have this concept of a health data utility. What we are seeing is that there are so many people from outside of health who want to use health data. And then there are different groups within health who have data. Lots of research data sets exist.

There is data that we actually hold, but it is standardized within a province, but it is not standardized across the country. We spend quite a lot of work what we

call harmonizing data for people who we just know will – for example, physician billing is based on individual provincial fee codes. Nobody is going to open up the physician fee code discussion. That is data that will always be harmonized we think and kind of have an overlay to it.

But the piece and the reason I put this slide up is I think a lot of the work that we are thinking of is around data governance. It is a missing piece. Who regulates what is in the public good, what overall standards are. We will have obviously a lot of standards that CIHI is kind of in charge of, but not all of them.

There is a whole burgeoning and then who fulfills data requests, who fulfills data requests for linked data that is held by different organizations. That is an area where we are spending an awful lot of time on and it is something where common terminologies and vocabulary will make things much easier.

For I-11, things that we are up to are we, in partnership with the University of Calgary, are doing field trials for I-11. The key piece for us is that all data submission is voluntary and all decisions to switch to a new version of the ICD would be voluntary at a provincial level.

What we have to do is try and – but that does not make any sense. We really have to try and get everyone on the same page to make the decision to switch. For us, we have to make a good case about what is – there are certainly things that are better in I-11 and are they better enough to justify the investment and the cost of upgrading.

We are doing some work on impact analysis, trying to figure out what does it mean for CIHI in terms of all of the many products and services we have trying to work with the provinces and trying to think what it means for them, what it means for the vendor community.

We are working with France on our translation and validation. We are beginning to just start – we are just starting talking about I-11. People have gotten over I-10 now. We are talking about it. I think we are hosting or not CIHI specifically, but Canada is hosting the WHO-FIC conference in Banff. I think that that will be a good place for us to launch I-11 in a little bit more proactive way. That is a bit about where we are at CIHI.

Thank you for sharing. It has been – like just the two hours that I have been here have been incredibly informative for me just in terms of understanding some of the fundamental differences in context around the voluntary encouragement, trying to build consensus around standards

and terminologies versus a regulatory approach and just some really different pieces at play. But hopefully there is enough income and that there is some learning here.

I am happy to take any questions or comments. I do not know if we have a bit of time.

DR. CHUTE: Chris Chute, Johns Hopkins. Many people have characterized the clinical modifications, the German modification, Canadian, Australian, American CM as self-inflicted wounds for international comparability. And the notion was a vision was put forth that as these continue to evolve, they would choose to incrementally approach an ICD-11 model or framework to make the evolution more graceful and indeed to make international comparability to more or less realign these modifications that are persisting. Has that been discussed in Canada? Would there be any enthusiasm for that?

MS. MORRIS: It has 100 percent been discussed. I would say that there is not a lot of enthusiasm at the moment for it. But we still have some runway I think before we are implementing I-11. In concept, we do tons of work with international comparisons. We do a lot of work with the OECD. We do a lot of work bilaterally with other countries. We certainly see the value in common standards. I think it is trying to figure out a way around where some

of our modifications have been and is there another way to capture the additional information.

I would say conceptually people are behind it in practice. The committee that lobbied for the Canadian modifications in the first place would still be looking for those modifications.

DR. MCDONALD: There was a project in Ontario for pediatrics called ECHIN(phonetic). Is that tied in to any of this at all? I think it covered all the hospitals and most of the pediatricians in Ontario.

MS. MORRIS: We are definitely aware of it and we had people sitting on the steering committee for it. It would be hard for me to give you any more specifics than that.

I would say that the good news for us is that typically when people are trying to do new things and trying to do new things on a multi-site or a multi-province basis, we typically get invited so that we are aware of it and can ideally build some of the learnings into future work.

DR. MCDONALD: That has been around for probably 15 to 20 years.

MR. ARGES: I had a question. You used the term chart of accounts as one of the things that you gather in Canada. I am trying to understand the usage of it in

Canada. I think I know how we used it here in the states, but is this a report that goes out from the facilities that operate to the provinces?

MS. MORRIS: Yes. It does two things. It captures dollars and it captures units of productivity. It would capture FTEs or nursing hours, for example, by unit somehow so that you can actually use the comments or more specifically one of the changes just as an example of a Canadian modification, but for LOINC, is trying to come up with how to define a lab test so that we can all count lab tests the same way. You can sort of see how much money is spent on lab tests.

MR. ARGES: It is a little different than the US. When I think of chart of accounts, it is really simply in counting of where you put the revenues, the expenses, and categorizing expenses and where it goes on the balance sheet. In essence, the chart of – what you are describing are really components of operational utilization. It is FTEs, number of labs, test run per FTE or something along those lines. It is a performance sort of --

MS. MORRIS: The MIS system has both. It actually has a common way of categorizing your expenses. It is not a balance sheet. It would be an income statement of both revenue and expenses. You could see, for example, there is an ancillary revenue. You can see how much hospitals across

the country make from parking fees, as an example. But there would also be some kind of unit of productivity attached to that. There is both a unit count and a financial number in each line of the accounts.

DR. STEAD: Do your intervention code set – is that one set that is used across different types of facilities or is that related to inpatient only? Is it used for both inpatient and outpatient, for example?

MS. MORRIS: It is for sure used for inpatient/outpatient and emergency. I am trying to think of is it used beyond an acute care world. If it is, it is not used widely.

DR. STEAD: Is it used for things that in our world we would call hospital based and physician practice based?

MS. MORRIS: It is used hospital based. Physician practice base – we would have information on some physician group practices or we would have information in remote areas on nursing stations where we would have information using that classification.

One of our gaps, I would say, is having good information on primary health care. It is not used there.

DR. STEAD: How much is SNOMED used in Canada?

MS. MORRIS: There is probably some SNOMED used in every province, but it is not used in a well-coordinated

way partly because I think that the way – the way SNOMED got into the system a lot of it was around – if you recall, InfoWay is the organization that had both SNOMED and LOINC. It was a condition of matching funding for an EHR implementation would be embedding either SNOMED or LOINC depending on the nature of the system.

MS. KLOSS: I have another question about the intervention. How consistent is your intervention approach to what the direction that we understand WHO-FIC is going in terms of developing some international classification of interventions. Do you have a feel for that?

MS. MORRIS: I cannot give you the detail on that, but my folks would tell me that it is quite consistent conceptually. I would say that they would say that they were informed by early ICHI work and are sharing the Canadian experience quite heavily with the ICHI developers.

MS. PICKETT: To continue on that light, with the development of ICHI, basically what WHO and the various collaborating centers that had a wealth of experience in developing their own procedure codes did was to try to come together with ultimately a framework, a backbone so that for countries that do have their own procedure intervention coding system that it would bear some similarity so that you could map back to something so that you could get comparable statistics out of it at the end. That was a key

concern so that it was not built solely on reimbursement as some of the procedure coding systems are in other countries, but it also was not just totally statistically based. A lot of thought and effort did go into trying to figure out what was the best way to scope and develop ICHI.

DR. ANDERSON: I am wondering if you could comment. A number of us in this country looked at Canada with some envy a decade or so ago when you seem to go through a relatively uneventful and straightforward transition from ICD-9 to ICD-10. Now, of course, I know that there were some delays in Quebec related to the French translation and so forth. And then also with procedure codes, we have this long tradition of two completely different coding systems for inpatient and outpatient procedure coding whereas you have a unified system. Do you have any thoughts about what factors have contributed to your success in these areas in Canada in implementing more consistent terminologies in a timelier manner? Does it just have to do with the size of the country? Does it have to do with the power of stakeholders? Does it have to do with CIHI's unique role? What are some of the factors?

MS. MORRIS: I think while I would like to chock it all up to our great persuasiveness and I honestly do think that that does help. It is an area of expertise that a lot of provinces or territories would not have on their

own. They look to us to come up with reasonable recommendations for them. I think to date we have generally steered them down a good path. But there is absolutely a scale kind of piece to that.

Outside of Ontario, there is – like no place is very big and they are building their own system. Honestly even the capacity to support two different intervention coding systems probably is not there. I think geography and numbers probably play in our favor as well.

I would say that we also have a history of good consensus building. I think the one thing that CIHI can do is somebody called it convening power, but we can actually bring vendors and governments and clinicians to honestly a single table and have a good structured meeting and have a good rational discussion about things and typically end up at some often imperfect, but at least a consensus on a way forward.

MS. KLOSS: Thank you very much, Kathleen. I think you helped us a lot transition our thinking because our topic when we come back from break is governance and coordination. I know I overheard some discussion as we walked around about people's knowledge of how they are organized in Australia and other parts of the world. Maybe some of those examples will come out in this discussion.

Now just because it is kind of the time of the afternoon when we slump, we are going to really mess you up. We made the decision in planning that that before we went into our third and final breakout group, we are going to reconstruct groups just to keep us out of our comfort zone. If you will just allow me to give some instructions on how we are going to create this chaos, it should not take very long. I am going to go group by group. This is Alix Goss. Stand up. Alix number one. Joining Alix at 3 o'clock will be Steve, Nelly, Ben, Felicia. Rich Landon. Joining Rich at 3 o'clock is Sue Bowman, Chris Chute, Leslie, Pierre. You could just take your tent cards with you and your materials and move along. Nick Coussoule right here. Joining Nick will be George, Kathleen, Bill, and Dan. Vickie. Joining Vickie will be Shelly, Clem, Matt, and Donna. Dave Ross. Joining Dave will be Jim, Ben, Lynn, and Susan. Bob Phillips. Joining Bob will be Kathleen, both Patricks and Margaret. And Lee Cornelius. Joining lee will be Bob Anderson, Vivian, Diana, and John White.

(Breakout)

Agenda Item: Discussion 3 Report Out

MS. KLOSS: We are doing really well here. Thank you so much. It has been a long day and I know it is hard to keep the energy level up and we really appreciate it. Let's report out. We are going to start with Group 7 and

work our way down. Never mind, we will start at 1. Very flexible. Where is 1? I lost 1. Lee, are you ready?

DR. CLARKE: Let me just talk about the opportunities to improve coordination. We talked about how much we do need to have stakeholders talking together and not just on a national level, but internationally. One example that we actually used is – I just recently started doing some work with SNOMED around common terminology and improvement in terminology for mental disorders. I remember when we got to the table and started talking with Jane Millard. What she talked about was the process that the dental association is actually going through and that they were a prime example and we could follow that. I thought that was kind of interesting.

When I am talking here to Jean, she was actually talking, yes, it is an international process, but you do have many Americans at the table. Even though it is an international thing, you do have enough representation of Americans or from the US so that whatever is decided there is applicable to the United States as well so bringing those stakeholders together.

And then also we need to incentivize participation. That can involve money of course because money talks and also participation like just some incentives. If you participate in a process, you have to

participate in a process for standards to be considered for adoption. If you participate in this coming together and coordinating then your standards will be considered for adoption. That is an example of that.

And then we also think that there should be some flexibility and openness for people coming at the table so there are different groups.

What is the second one? Characteristics for the most useful governance model. We definitely need to have some commitment of resources. It is a very expensive process and many people are volunteering their time, but you do need to have some commitment from enough resources, not just to bring the people to the table, but once we have also done all of that, what about the expertise in training the next generation? You have to have some money in there and then also just have some personal value for stakeholders. For people to adopt and to participate in the coordination and participate in the process, they must have some kind of personal value. It must be meaningful to them.

This one came from John, which I actually do like. The model that could be used. Useful governance model in the private sector that aligns with business processes plus so this is in combination with useful governance model in the public sector that is aligned with public interest. There is variability in that. Sometimes it is going to lean

more towards the business model and sometimes towards the public sector model. It really needs to identify the best model to achieve the goal that is at hand.

And then to identify key governance and coordination principles. We have talked about this all today. Interoperability. That is on a global – interoperability on a global standard that allows then for national and local individuality so some flexibility there. And then of course that interoperability has to match the use case so neat, clear scope when you are talking about interoperability and then also making sure that we have input from vendors, the people at the table. Vendors, consumers, and innovators.

And some of our insights that we wish to share is that it takes dedication. You need to have the right people, the right skills and the right knowledge set. You need to have the right expertise at the table and you need to understand and know when to leverage technology. Those are technological organizations, for example. Google, Apple, et cetera. Those are some of the things that we talked about.

MS. KLOSS: We are going here. Six is next.

DR. BLAKE: We had a lively discussion about the topic and the first thing that we – an important thing that we focused on is that you are really asking us about two

separate questions. They are on a spectrum coordination implied to us that it was not governing the actual operations of the terminology organizations or the usage. Governance is much stricter than that.

Governance also depends at least in this country on the willingness of the governed to actually be governed. We saw the coordination function is coming first because that then to use another analogy is kind of like dating before you get married so that you are in a coordinating relationship where you are actually getting to know one another and you are able to see what the value could be if at some point a governance model is developed.

We also talked quite a bit several times about the need for consistent funding. We thought that it would be challenging at times for that to be obtained from government. That we really think that there is a need for shall we say an apolitical process and that it would be a process where a model for that could be a public-private partnership of which there are a number. A new one is the National Evaluation System for Health Technology, which is FDA's public-private partnership. Another one of longer duration is the National Quality Forum. We would recommend examining those models and the opportunities.

And then we thought that there should be a widely representative participant base that covers all

stakeholders. We also called out vendors as being absolutely critical participants to something like this.

When we looked at characteristics of the most useful governance model, again, public-private partnerships, and that the participants are willing to be governed and that this might require in the governing shall we say bylaws different levels of agreement that are required for different types of decisions. Some might be just based on simple majorities. Others could be based on super majorities at different levels because there was concern if we got to a 50 percent plus 1 kind of situation that the governed would be rebellious.

The other insights. We thought that if there is a coordinating dating experience, the key value of that would be to really tackle the issue of duplication of coding sets and of efforts and that there would be a close look at where there were good opportunities to be able to make progress there.

We thought the other was to minimize the whiplash that is felt by many of the stakeholders, vendors, end users by being able to say can we agree on a standard frequency of updates. We were struck by the Canadian agreement that we will update ICD-10 every three years. That is predictability. That can be integrated into your business models.

We thought that there were some best practices for governance that would clearly need to be built into whatever eventually emerges.

DR. MCDONALD: This is a deja vous all over again. Didn't we have WEDI, which is this coordinating group for standards? We still have it.

There is another one too now. Dan, you are involved with some standard group. What is called?

PARTICIPANT: HSC.

DR. MCDONALD: We can look forward to some more.

DR. BLAKE: Then the question would be if this is already in place, why would the question be asked --

DR. MCDONALD: I did not suggest that it is in place. I suggested we tried these kinds of things. We should remember how to do it differently or whatever.

PARTICIPANT: Some of us do not know what WEDI is.

DR. NARCISSI: It is the Workgroup for Electronic Data Interchange. We are trying to move off of all the whole EDI thing and get into other areas. We are named in the HIPAA law as a consultant in our huge education arm too. Standards and --

MR. VREEMAN: The other one is the Health Standards Collaborative. It is made up of the executive leads from health care standards developers. It is focused around the US model and it is HL7, X12, Regenstrief and

others. It is an executive forum for collaboration and idea sharing coordination as well.

MS. GOSS: I would like to build on the HSC aspect and that it evolved from what was the Standards Chart Organization. I am very familiar with this because I helped create it. It was actually replacement and Chris Chute should remember these days from the Health Informatics Standards Board. There are a number of repeat attempts to get all the SDOs and we are talking about transaction standards in these examples. We are not talking code set standards. I think there is still a gap to your point that we need an ecosystem for vocabularies that can learn from the trials and tribulations of the transaction standards.

DR. BLAKE: We actually briefly discussed that that there is an environment that is – it has now been confirmed kind of littered with experiences, the tough experiences of what not to repeat and experiences of terminology organizations having collaboratives that have also been very successful or fruitful so to learn from the mistakes and from the wins.

DR. CIMINO: This is the conservative table. You can see we are for small governance. In keeping with our conservative perspective, we are for arranged marriages as opposed to dating. We want to actually ask the organizations that have overlapping domains to work

together or explain to us why they are not working together to either collaborative to reconcile their terminologies where they have overlap. Examples are SNOMED and LOINC for laboratories or CPT and PCS for procedures. These are areas where it is not necessarily the same domain. Maybe lab and LOINC and SNOMED are the same. We need to know why they are not working together if they cannot reconcile that.

PCS and CPT. We think those are really synergistic terminologies or orthogonal, but they need to coordinate. If one of them is talking about the reason for an appendectomy and the other one is talking about an appendectomy, they should have the same term appendectomy at least so that there is coordination there. They need to explain to the public what those differences are so that people understand how to use them appropriately and they need to provide valid crosswalks for being able to go from one to another where that is appropriate.

In terms of key governance and principles, open standards with the ability for all stakeholders to participate and contribute, be represented.

We also think and I heard something about commitment of resources and specifically for maintenance, a maintenance process that the organization – that the standards organization says here is how we going to maintain and we are committed to this. Here is our

sustainability model. We are not just going to say we are going to maintain it. Here is our model for how we are going to pay for the maintenance or how we are going to get volunteers to participate or whatever the mechanism is. That NCVHS should periodically review this commitment and see if they are really sticking to these requirements.

We had under governance models – we talked a lot about who pays for this and try to figure out. We think that whoever benefits should pay for it, but it sometimes difficult to figure out who that is. You have somebody who is billing somebody else. The biller and the billee, the payee and payer. They are benefiting from that exchange of data. One wants the data in a certain form and the other wants to get paid. They both benefit so they should be supporting that. That is the model. That is the model for CPT. There may be ways to do that for others as well.

Other governance model. The open source license. The ability to rapidly develop the content of terminology. LOINC has a 100-day turnaround process to get new terms into LOINC and then – that quickly. We had talked earlier about licensing as an impediment, but LOINC does not have that kind of license problem.

And then where are there terminologies that are doing development with public input there should be actually access to the comments of the internal comments.

The committee in the ICD was the example given that you can go and participate and say what you want, but then you never know what happened behind the closed doors and there should be public access to the comments that lead to those changes.

MS. KLOSS: Who wants to go next?

MS. WIGGS-HARRIS: I am actually going to start with our other insights since some of the other information that has been shared that we covered has already been shared. We had a very rich conversation here. One of our insights is that we need to acknowledge the barriers whether they are historical, political, or cultural that keeps getting in the way of us moving forward because we can have the best coordination strategies. We can talk about the characteristics of the governance roles. But if we do not find a way to put the interest of the public good over business models, somebody will be in this room next year and the year after having the exact same conversation.

PARTICIPANT: Five years from now.

MS. WIGGS-HARRIS: Five years from now.

Going on to some of the near-term opportunities, similar to Table 5, we did talk about managing those obvious domain overlaps, for example, RxNorm and CVX.

We also discussed similar to Table 7 learning from efforts that are underway so we are again not replicating things unnecessary.

In terms of identifying key governance and coordination principles, we talked about having a clear vision of what we want or need to achieve. Also, we discussed incentives.

We discussed briefly the notion of having domain expertise, control the content of a governing body coordinating a structure to enable convergence over time. In terms of characteristics of the most governance models, we discussed authority, transparency, resources, which also came up at this table, and accountability to whatever that vision is. Does that cover it?

MR. VREEMAN: Our group talked about as far as opportunities to improve coordination, we talked about the development of a strategic plan for terminologies that categorize the importance of particular domains and the specific purposes of use for these terminologies.

With that and sort of corresponding to that was a critical evaluation of the cadence of update based on input from all stakeholders. We riffed on the Canadian three-year update model and the different benefits and cons to have that across different domains. But the idea was to look

critically at what that cadence is with input from a lot of folks.

Some of the characteristics that we discussed as being useful in governance models were, one, having a specific way of incorporating the consensus-building process meaning that is an arm that feeds into governance itself. In addition, a characteristic of balancing different stakeholder priorities, a mechanism for doing that including both public perspectives and private perspectives. Being responsive to end users that are the implementers or users of these terminologies as well as having a global perspective.

We identified two main principles for governance and coordination. One was the idea of an open and clear process for curation so that people understood how to participate and have an opportunity to do so. And the second was the principle of parsimony, which is narrowing the selection for particular purposes or domains. We should not have a million terminologies for one particular domain.

Two, other insights that we talked about. One was specifically recognizing the role of the federal government as a catalyst for improved governance both from organizations such as CMS and VA. And specifically we also talked about the evolving role of machine learning and natural language processing as it relates to the use of

code systems. This is sort of an area to keep our eyes on, the insights, predictions and so forth that we can make continue to be evaluated. It is just worth mentioning here as an evolving area.

DR. MCDONALD: We talked about models we were talking about here. You might describe the RSNA or RadLex merged sort of and the coordination done with that. I forgot about it myself until it was brought up somewhere else.

MR. VREEMAN: I think there are a couple of different models of shared governance. One example is a joint effort to literally unify two different terminology products that have a shared or overlapping space and then share going forward the governance, maintenance, and update of that. This was specifically LOINC and the RadLex Playbook partnering with the RSNA as an example of a successful approach that brought together two groups and unified the product itself.

MS. BOWMAN: Like many of the other groups, we also talked about minimizing overlap and redundancy among the vocabularies and terminologies by establishing some boundaries and domains to make sure that we could have less overlap. But also, we talked about even in cases where another terminology exists and could be used, that should be done more often. An example of that is where ICD-10 and

PCS has been creating specific codes for administration of drugs rather than do that within the PCS code set. Why not go get the concepts they need from a drug terminology and not reinvent the wheel within that code set, which is beyond the domain and scope that that code set was intended for?

Also, under opportunities for improving coordination, we talked about how systems need to be interoperable and underlying systems that host the standard need to be very agile. An example of that we gave – Pierre is not here so I guess I can throw CMS under the bus. We specifically talked about some of the CMS systems and being not agile enough to make some of the changes and move forward in the modern world like much of the private sector has been able to do.

Characteristics of useful governance models included transparent and open. Evidence-based instead of advocacy based and what we meant by that is focus on some of the established criteria for content acceptance and look at what evidence there is for adding a concept to a particular terminology and vocabulary, not just who screams the loudest for a new concept to be added.

Another characteristic of the governance model is there should be valid use cases that kind of goes along with the evidence-based principle.

And then for key governance and coordination principles, the main one we came up with again is to proactively use established concepts from existing standards perhaps by going into UMLS and finding if there is already a concept that exists in another terminology instead of recreating additional terminology. Did I miss anything? Thank you.

MS. LIPON: We had a few things that are a little bit different. With regards to opportunities to improve coordination, we actually talked about the inventory that has been started, lots of gaps identified, but completing that inventory of the standards out there including the scope that they cover and then making that available electronically and easily accessible by users would take us a long ways just in what is out there and what could I use because it does not really exist right now.

And then identifying the high priority areas of coordination. Instead of trying to boil the ocean, what are the areas that are causing the most in terms of burdensome and pick those areas to try to do some coordination? We only had two under that. I could not think of a third.

The characteristics of the most useful governance models. We talked a little bit about thinking about the logic of how standards would be deployed electronically with regards to how you govern would be useful. We talked

about the standard models should be based on health care delivery needs. That is similar to the use case stuff versus regulatory needs or lobbying needs or anything like that. And that the standards should be governed by SMIs with a common interest of some sort. That would be a useful characteristic.

Governance and coordination principles. We talked about transparency, traceability in terms of the decisions that have been made in the past. Nobody really kind of knows how we got to some decisions and so some type of traceability would be useful.

Some thought to interoperability in terms of the existing standards that already exists. If you are picking a new standard or you are going to use a new standard, some thought in regards to how it integrates with the ones you already have in place and is there interoperability or not.

It should be inclusive of all the major stakeholders. I think a lot of our standards get developed in a very small vacuum and industry in particular is not always involved. We thought that that should be a principle. We had five in this one.

We then had easier, faster, and less expensive. Those should be a principle. And then less is more. That was a principle.

And then some of the other insights. We actually started our conversation talking a little bit about other countries and maybe some things that are working in other countries. We had a little bit of a discussion around how Canada allows you to natively download the standards as is kind of thing, which in a lot of cases will allow less errors and less breakages where in some cases, some of the packaging that is done sometimes causes errors and breakages of the way it is done in the US in particular.

And then we talked a little bit about the Australian model in terms of some of the work that they have done previous before they became the agency. They had done quite a bit of work really focused on how standards could be consumed by industry in terms of their API work and stuff. We thought that might be a place to look.

MS. KLOSS: Let’s just give ourselves a really round of applause. Awesome work today. I am just so excited.

Agenda Item: Recap of Insights from the Day and Discussion

MS. KLOSS: We have just a few minutes to wrap up. While you thought that Bill and I were up here playing solitaire while you were working so hard, we were actually trying to do a little high-level synthesis just to get our juices flowing before we break for today and understand

that these were created by listening and not calling over all of the notes, which we are going to pull together.

We broke it into a couple of chunks, things that seem to be recurring in terms of near-term opportunities and things that were longer term. We did not attempt to make any decision about what near-term versus – but things that popped out in our minds could begin to be put in a letter to the secretary and be turned into a tangible recommendation short-term.

DR. STEAD: One way is as we talk near-term versus long-term, instead of assigning a specific year to it, what we are really thinking about is near-term might be those things about which we all agree and we can maybe just move forward. Long-term is more of our vision for where we want to land and we have some comments on the path between one and the other. But instead of having a specific time period, we are really trying to say the things that are sufficiently – sufficient consensus about, we could move forward now and get some near-term benefit. That is what we are really talking about and distinguishing where we know as we move beyond that the level of agreement is going to be more variable and therefore the path that you work your way there is going to be longer.

MS. KLOSS: And we are going to need to do more study because we do not understand it well enough to know

what that path actually is. But I think the focus that we have had today on principles and the excellent job that you have done in identifying them will come together in quite a robust set. We think that there can be some articulation of principles that will guide adoption and that that is pretty obvious that clearer boundaries, clearer statements of purpose, clearer understanding of when a terminology or vocabulary is to be used has come up a number of times.

DR. STEAD: Related to that, one piece is that if a terminology and vocabulary standard is going to be adopted, we think it might have a clear boundary or scope, purpose and when to use it. Without those things, it is very hard to evaluate.

Then there needs to be evaluation of its uses, the things people have said about who is using it for what, its usability, fitness for use, its currency, and its ability to stay current and its cost benefit in achieving the purpose.

Then an adoption process that is suitable to terminology and vocabulary. I think the point that was made earlier that the consensus process around messaging standards where things have to fit together, think of the train track age, is very different than the process for curation of a constantly evolving terminology and the adoption process should be tuned, if you will, to the one

that works for T and V. We ought to really distinguish that these are different and there is therefore leverage in that.

PARTICIPANT: Is there –

DR. STEAD: There are three slides here. There is actually four. This is our attempt at near-term because we are trying to keep this --

MS. KLOSS: We are trying to size this elephant. The principles again for updating a name standard. We discussed the need for curation that has backward compatibility, transparent in terms of adds, changes, deletions, the rationale for why changes have been made.

We have heard about the need for a published cadence that reflects explicit again cost benefit, understanding of the cost and benefit.

DR. STEAD: In this case, we are talking about the cost and benefit of adoption and here we are talking about cost and benefit of cadence assuming that the cadence will be different for different terminologies to achieve the purpose of the update. We want to be able to match those. But whatever it is should be explicit and published. The idea and the difference between one size fits all and predictability.

DR. WHITE: Meaning that, for example, a change that reflected a gradual evolution and a concept would be

on a different timescale than a change where the original was killing people and the new version did not kill people.

DR. STEAD: Correct. Well said.

MS. KLOSS: And then with regard to cadence to this issue that got surfaced that we do not need to go through full regulatory for ICD, it is just an artifact of the way the law was written and perhaps that could be an area where the law could be changed to allow ICD to be version updates to progress the way CPT and SNOMED and other named terminologies progressed.

On dissemination, again, we are thinking near-term, adopting electronic means including implementation and mapping tools and addressing the issues of cost and licensing barriers that came up several times today.

DR. STEAD: In our attempt to -- this is obviously an early draft. In the definition of near-term, which are things that if we recommended would be – there would be pretty clear consensus that we should move ahead with.

DR. MCDONALD: -- what compatibility means in terms of vocabulary?

DR. STEAD: To me, it means don't change. Don't take a code that was used for a meaning and changed it so it means something else is the most obvious example.

DR. WHITE: In general, I like it. I especially like the – version updates from regulatory process. What I

would encourage you to do is that as you go through and flesh these out and turn these into a more finished product, we have a lovely environmental scan. I would love to see in the final product this is the way things are currently done and this is the way things ought to be done differently to reflect these opportunities, to achieve these opportunities where you can actually suggest that. There may be places where you cannot be quite as specific.

In some of these, I think you could probably argue are happening to one degree or another in certain processes – of excellence. But obviously, you want to drive that more broadly across the environment. That would be useful for somebody who is getting the recommendations.

DR. BROWN: I think one point that we spent an amount of time talking about at our table that may not be quite reflected there is the idea that there should be some systematic criteria or approach, not just transparency, but a systematic criterion or approach for evaluating potential updates and that could incorporate. There would be a cadence of course, but the process of evaluating whether a particular code, for example, should be added or a particular concept should be added might depend a prioritization of the importance of the underlying condition, what the public health circumstances, what the potential uses of those additional codes would be, what the

return on investment would be associated with using that code and so forth. It may be a little bit in there, but just to flesh that out a little bit more.

DR. STEAD: Let’s go to the next slide, Linda.

MS. KLOSS: We do not know where this falls. We are putting any near-term or longer-term on it. It is just something that seemed to be a recurring theme here that we need a more deliberate pathway toward convergence.

DR. STEAD: I guess I would put – in my sense, this is something that we should start trying to do now, but that will take longer than the near-term to do. It is part of the path from the near-term things to the long-term vision. The path would at least include things like this.

MS. KLOSS: First bullet is certainly one that everybody agrees on and talks about and NCVHS has written extensively about. There is a convergence between clinical and administrative domains and nowhere is it felt kind of more painfully than in terminology and vocabulary where in some ways, the two worlds have diverged rather than converged and we need to drive that path toward greater convergence. Speak over that redundancy.

DR. STEAD: The second idea is that we want to distinguish between purposeful overlap and redundant effort because if two different terminologies have the same – cover concepts that have overlapping scope, but the purpose

of the terminologies are different of what you are using them for. Then the terminologies are likely to be different also even though there will be overlap in the scope of the content.

We think we need to distinguish between particularly in a terminology world where having – because there have been several comments that we have different perspectives. You actually need the terminologies to represent each of those perspectives validly. And yet you need to see some – you need a way of seeing how they align with each other. From my perch and we tried to write this into the environmental scan, this is actually one of the great wins of the Unified Medical Language System Metathesaurus and that it is set side by side terminologies that do have different purposes and the concepts – when those terms are related to the concepts they have in concepts. In essence, those links create very rich definitions that are not part of any of the terminologies themselves. That is an example of what I mean by the fact that richness in terminology when that richness reflects the differences and perspectives of what you are trying to capture, which is important. We do not want to try to take that out. We actually want to make it explicit. This isn't as simple as it could be.

MS. KLOSS: The third bullet is I think we have touched on this too with regards to name standards. There has to be some limited optionality for interoperability and comparability. But there could be some flexibility in versioning through convergent thinking. That point came through.

DR. STEAD: And parsimony was another word mentioned, which could go for limited optionality. It might be easier to absorb. But we did not have that word when we were making the slide. You suggested that more recently.

DR. MCDONALD: It is not important, but you guys are doing a nice a job at the Academy Awards. One does one. The other one does one. It is kind of nice.

MS. KLOSS: We have not rehearsed.

The last one is not to suggest that this is not going on, but it is going on in silos. The research and evaluation of how model and what concepts need to be added and not necessarily going on perhaps at the level it needs to be and in a way that – convergence.

DR. STEAD: This is, for example, where we would plug in the comment that came out of maybe the last report out around the implications of machine learning, for example.

DR. ROMANO: Can you give one example for bullet three just a little more explanation?

DR. STEAD: If there are two terminologies and they have the same purpose, we think we should only name one. We should not give you choice about whether you use that one or not.

DR. ROMANO: It is not – within a terminology. It is choice of terminology.

DR. STEAD: This is about choice of terminology. You offset that by giving people flexibility in the versioning that lets them have – one of the concepts we have talked about in the predictability roadmap work is that we should be constantly elevating the floor of the oldest version that everybody should be to now while allowing – while having a versioning infrastructure that makes it easy to allow people that have a business reason for being at the absolute leading edge or in fact being ahead of the leading edge of a version to do that in a way that drives progress. And then we advance the floor as it reaches the criteria that were on the first – there needs to be some flexibility in that, but less so in terms of the name standards.

Did I make that clear or did I make it more muddy, Steve?

DR. ROMANO: Would another way of saying it perhaps be allow multiple versions of one winner?

DR. STEAD: Correct.

MS. KLOSS: That would be clear.

Then we left blank space for the insights that you have just delivered up and we will get those digested by breakfast time. How about that?

And then went on to some things that we heard that seem to be long-term.

DR. STEAD: This is an attempt to get at the piece here is understanding where we want to arrive. And we are guessing that this will be fairly controversial, maybe we are wrong. But we hope it is in the right general lake of the direction we would need to go over the long-term. The idea of a single dissemination resource center possibly related to some form of a coordination center related to the slide we have not filled in.

Then put a stake in the ground. We ought to be using clinically useful terminologies in the electronic health record. We put examples of what some of those clinical terminologies might be.

In a world where we are trying to manage patients across the continuum in population health, we need to decouple intervention or procedure codes from the facility type or location. Those can be two things that get associated with one another in a way that lets us see how procedures – commonality of what a procedure is as it moves

from inpatient to outpatient to home, which is what keeps happening.

We need a way to then calculate the payment classes from the clinical content and a way to calculate the quality measures from the clinical content so that that is not redundant entry. It can be a different view. It is in essence an aggregation or abstraction of the information that is in the clinical form for a different purpose. To make all that work for things that are not health care or not only health care, we need to expand the scope of the name terminology standards to include vitals in public health, population health, social and behavioral determinants, mental health and others. This little piece, as Linda pointed out, is the bridge to tomorrow where we are starting to talk about gaps. That is a possible destination that we might seek to go. It may not be the right one, but we hope it is at least directionally useful.

DR. MCDONALD: Some of these things are not that radical. These are not such a stretch. But I point out that the vitals is already a name standard in HIPAA. Their LOINC codes are already specified, for example. That is not a stretch at all.

I think some of these things might be harder than others, but these are not long range things in my mind. Do you have another one that is a really tough one?

DR. STEAD: Clem, I would never characterize you as a person that was thinking anywhere other than the real long-term. If everybody agrees this is on target or can be easily edited where it is, we would obviously be glad to move it earlier.

MS. KLOSS: We have to do it. These conceptually may be it, but getting there.

MS. LEON-CHISEN: So that you do not think these are easy things to accomplish, I may want to remind you that the issue – the coupling intervention procedure codes from facility type sounds very much like what was being fought over 25 years ago about a single procedure classification system. I would say that that was probably the biggest obstacle to having an agreement about moving to ICD-10. I think that in general people agree, yes, diagnosis coding. Yes, possibly we can learn to apply more diagnosis code and extra digits and all that, but this is not an easy list.

PARTICIPANT: We can have an offline discussion because CPT is using the hospital too. I was at those meetings.

MS. LEON-CHISEN: -- those painful discussions like I know Sue does. I do not want people to leave with the idea that these are very simple goals that can be achieved that have already been worked on. I think this

also ties to something that our group talked about in terms of a governance and some of the barriers and some of those where historical, political, and cultural. I think that is going to be a barrier once again if we think that we are going to go down the path of looking at a single procedure classification system.

MR. HAMLIN: I just want to take issue with your second bullet. They are not that far out there because we already are calculating quality measures from clinical content. What I want to substitute that bullet with is calculate decision support from clinical content or inform decision support from clinical content because that is really where we need to go. We need to use these standard terminologies across the care continuum to inform decision support and not really care so much about the quality measurement retrospective kind of assessment.

DR. STEAD: I would just advocate that we add instead of replace because I can tell you most people are not seamlessly calculating their quality measures from clinically meaningful recording in the electronic health record. If you can show me a clinician today that thinks they are doing in their electronic health record – clinically meaningful, I would love to see them. It has been a while.

MS. PICKETT: I just wanted to pick up on the comment that Nellie had made about the historical nature of this. For those of you who were not part of all the original hearings that were held by the National Committee on Vital and Health Statistics and all of the named code sets, I invite you to go to the NCVHS website because the summary of all of those issues are still on the website. The letter of recommendation from the committee to the secretary about the HIPAA code sets specifically is still on the website. If you were not down in the weeds back then, you have not lost your opportunity to revisit it because that information is still there. As Nellie pointed out and others, it is still very relevant to the work that we are looking at now.

MS. KLOSS: Absolutely. But it is 20 years hence and we have electronic health records now.

DR. STEAD: Again, let me establish the context. We are hoping that first slide or some successor are the things that agree or not just we in this room, but the process we used to vet them before we turn it into a letter of recommendation would be things which the industry would have consensus. The time was right to move forward with them and that we were able to give actionable examples, as John said, so it was an actionable set of things that really began to move the ball.

We are hoping the second slide which gets at a path toward convergence are things which people could agree would be good steps to begin to take and this is an attempt to paint a picture of where we might come out. My best example of that – those of you that also want to go to the NCVHS website, look at the 2001 graphic that laid out the picture of what the next generation health statistics might look like. That graphic in retrospect is amazingly on target and it reflects all the things we are talking about and things like social and behavioral determinants of health and equity, et cetera.

This is an attempt to get that kind of a picture so that some number of us can begin to think about how we really use that path forward to get to something like that. We are not suggesting that we would make a recommendation to the secretary to do this. We are trying to say we need to collectively agree on a picture of what the ideal outcome might look like in some number of years just so we have it as we are moving forward.

I want people to think on this, sleep on it, help us know if there is a better way to tune this for that picture while making sure we spend most of our energy getting the near-term recommendations right and the path to convergence right.

DR. MCDONALD: I think it would be good and I think you probably intend to do this to tie this or recognize what is going on now because they have some momentum as well you know so that the secretary realizes we are all on the same page. That is number one.

The second thing is when we get into some of these other measurements of things that are difficult, I think we should cognizant of the difference between calling them codes like he is sick or he is depressed or he is on drugs versus some measure in a survey instrument type forum to quantify it. We kind of lose that distinction. There are tradeoffs, but just be conscious that you probably need them both.

DR. STEAD: Absolutely. I think you are getting at things like the validated question sets that allow an individual to self-report a social – correct.

Have we done enough damage for one day before we take public comment? John.

DR. WHITE: Almost enough damage. These are good recommendations. I have been sitting here kind of noodling on them. I have spent the past several years pitching stuff like this to political leaders whether it is my boss or my boss' boss, occasionally my boss' boss' boss, but also folks on the Hill, folks in the private sector.

I am going to say this lovingly. These are very wonky recommendations. We are wonky people so that is good. But you are going to need to anchor it in what you just said, which is that ideal world that you are looking for, but it cannot really be mom and apple pie.

I am going to encourage you to start with how does this make citizens' lives better. That is the ideal world, not just the ideal world where everybody kind of holds hand. But seriously like my mom, my wife, my kids. How does that make their lives better? Your mom, your wife, your kids. And then translate that into things that a secretary will care about or congressional leaders or congressional staff will care about because their constituents are going to care about them. I know you guys know that, but just reflecting on reading what was there. I am going to encourage you to come back that we all do this. We are here convened under the aegis of the federal government because we are doing this for the nation. Just try to anchor it in that and then you can say why you need that single dissemination resource center. Somebody is like why do you need that. Because it is going to save lives. But you need that chain of logic.

Agenda Item: Public Comment

MS. HINES: Anyone in the room who would like to submit a public comment to the committee? No one in the

audience. Are there any public comments submitted on the WebEx? We will wait one minute. They can submit via the WebEx dashboard or they can send us an email to the NCVHS box. I do not see any sign of public comment so I think we can close the public comment period. We will have a second public comment period before the lunch break tomorrow if anyone from the public would like to submit a comment by email or on the WebEx dashboard.

MS. KLOSS: We have had a couple of questions about tomorrow afternoon. It is a working session for the members of the committee, but we would love anybody who can stay and work with us to stay. Our formal meeting will adjourn at noon, but we are going to work until midafternoon. You are very welcome to stay and observe or participate or come to the table or whatever. It depends on your schedule.

DR. STEAD: Our goal in that block is to really come out with how we are going to get to the September Full Committee meeting. It is a little bit like what we were doing here trying to really pull it together into steps forward so that it does not sit on the vine very long.

MS. KLOSS: Just a reminder, if you are able to join us from six to seven, we have a little cash bar reception thing at the Hyatt place where many people are staying just to socially unwind after this challenging day.

DR. STEAD: Thanks to all of you to the level of engagement, the real content you each have brought to this is truly a gift to the country. Thank you.

(Whereupon, at 5:08 p.m., the meeting adjourned.)