Transcript

HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC) U.S. CORE DATA FOR INTEROPERABILITY TASK FORCE 2021 MEETING

June 22, 2021, 10:00 a.m. – 11:30 a.m. ET

VIRTUAL
Speakers

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leslie Kelly Hall</td>
<td>Engaging Patient Strategy</td>
<td>Co-Chair</td>
</tr>
<tr>
<td>Steven Lane</td>
<td>Sutter Health</td>
<td>Co-Chair</td>
</tr>
<tr>
<td>Ricky Bloomfield</td>
<td>Apple</td>
<td>Member</td>
</tr>
<tr>
<td>Hans Buitendijk</td>
<td>Cerner</td>
<td>Member</td>
</tr>
<tr>
<td>Grace Cordovano</td>
<td>Enlightening Results</td>
<td>Member</td>
</tr>
<tr>
<td>Jim Jirjis</td>
<td>HCA Healthcare</td>
<td>Member</td>
</tr>
<tr>
<td>Ken Kawamoto</td>
<td>University of Utah Health</td>
<td>Member</td>
</tr>
<tr>
<td>John Kilbourne</td>
<td>Department of Veterans Health Affairs</td>
<td>Member</td>
</tr>
<tr>
<td>Leslie Lenert</td>
<td>Medical University of South Carolina</td>
<td>Member</td>
</tr>
<tr>
<td>Clement McDonald</td>
<td>National Library of Medicine</td>
<td>Member</td>
</tr>
<tr>
<td>Aaron Miri</td>
<td>The University of Texas at Austin, Dell Medical School and UT Health Austin</td>
<td>Member</td>
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<tr>
<td>Brett Oliver</td>
<td>Baptist Health</td>
<td>Member</td>
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<tr>
<td>Mark Savage</td>
<td>Savage Consulting</td>
<td>Member</td>
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<tr>
<td>Michelle Schreiber</td>
<td>Centers for Medicare and Medicaid Services</td>
<td>Member</td>
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<tr>
<td>Abby Sears</td>
<td>OCHIN</td>
<td>Member</td>
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<tr>
<td>Sasha TerMaat</td>
<td>Epic</td>
<td>Member</td>
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<tr>
<td>Andrew Truscott</td>
<td>Accenture</td>
<td>Member</td>
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<tr>
<td>Sheryl Turney</td>
<td>Anthem, Inc.</td>
<td>Member</td>
</tr>
<tr>
<td>Daniel Vreeman</td>
<td>RTI International</td>
<td>Member</td>
</tr>
<tr>
<td>Denise Webb</td>
<td>Indiana Hemophilia and Thrombosis Center</td>
<td>Member</td>
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<td>Michael Berry</td>
<td>Office of the National Coordinator for Health Information Technology</td>
<td>Designated Federal Officer</td>
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<tr>
<td>Al Taylor</td>
<td>Office of the National Coordinator for Health Information Technology</td>
<td>Staff Lead</td>
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<tr>
<td>Steve Eichner</td>
<td>Texas Department of State Health Services</td>
<td>Presenter</td>
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<tr>
<td>Nedra Garrett</td>
<td>Centers for Disease Control and Prevention</td>
<td>Presenter</td>
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<td>Name</td>
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<td>Position</td>
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<td>Carolyn Petersen</td>
<td>Individual</td>
<td>Presenter</td>
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<tr>
<td>Janet Hamilton</td>
<td>Council of State and Territorial Epidemiologists (CSTE)</td>
<td>Presenter</td>
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Call to Order/Roll Call (00:00:00)

Operator
All lines are now bridged.

Mike Berry
Great. Thank you very much. Good morning everyone. I am Mike Berry with ONC. Welcome to the USCDI Task Force. We have several guests with us today that Steven and Leslie will introduce shortly. But I am going to open today’s meeting with roll call, and I will start with our co-chairs. Steven Lane?

Steven Lane
Good morning.

Mike Berry
Leslie Kelly Hall?

Leslie Kelly Hall
Good morning.

Mike Berry
Ricky Bloomfield? Hans Buitendijk? Grace Cordovano?

Grace Cordovano
Good morning.

Mike Berry
Jim Jirjis? Ken Kawamoto? John Kilbourne?

John Kilbourne
Good morning.

Mike Berry
Leslie Lenert? Clement McDonald? Aaron Miri? Brett Oliver? Mark Savage?

Mark Savage
Good morning.

Mike Berry
Michelle Schreiber? Abby Sears is on vacation, and she will be joining us at another time. Sasha TerMaat?

Sasha TerMaat
Good morning.

Mike Berry
Andrew Truscott?
Andrew Truscott
Good morning.

Mike Berry
Sheryl Turney?

Sheryl Turney
Good morning.

Mike Berry
Dan Vreeman?

Dan Vreeman
Good morning

Mike Berry
Good morning, and Denise Webb?

Denise Webb
Good morning.

Mike Berry
All right. Good morning everyone and thank you. I will now turn it over to our cochairs to get us started. Steve and Leslie take it away.

Past Meeting Notes (00:01:30)

Steven Lane
Thank you so much Mike. Thank you to everyone who has joined us extra early this morning on the West Coast. It is beautiful and foggy. I hope the rest of you are enjoying these first days of summer. We continue to post our past meeting notes to the website. I think we might be one meeting behind at this point, but those we get up there as soon as possible. Today, we are very fortunate to have some real experts in the field of public health informatics and interoperability. This is one of the areas of priority that we have identified as a task force, that we wanted to assure was being addressed in the evolutionary process for USCDI. We talked about it a bit, but this is our chance to dig deeply, as part of our phase three work, to understand what has been going on in the space of public health interoperability, and whether there are specific recommendations that our task force should be making to the HITAC and to ONC, with regards to supporting this. I want to acknowledge that a lot of tremendous work is going on in the space of public health informatics right now.

Obviously, it is stimulated by our experience with the pandemic. It is not required that, we as a task force, weigh in with further recommendations in this area. We have already identified public health as a priority use case. If there are specific data classes, data elements, in the domain of public health interoperability that we need to call out or have an opportunity to throw our support behind, I think that will be helpful. That was the reason that we organized this meeting today. As was mentioned, we have a number of guests
today. I know that at least some of them, it looks like all of them are now on audio, so we can introduce everybody. We do have the cochairs of the currently active ONC Public Health Data Systems Task Force, Janet Hamilton, and Carolyn Petersen with us today. That task force is working in parallel with our own. Some members of this task force are also participating in that task force.

This is the Tuesday task force, that is the Thursday task force. That task force is well down the path of completing its work and charge. We did not bring that charge to you. Basically, it is to help the government figure out how to spend the available money to improve public health data systems and their interoperability. I am going to let Carolyn and Janet introduce themselves in a moment and talk about the work of that task force. I do not believe that task force is specifically focused on USCDI. Our thought was to bring the task force leads from that one to this one, to listen to and participate in the discussion. If there are USCDI specific recommendations, there certainly would not be anything wrong with both of our task forces making those. The recommendations to the HITAC. Their recommendations are going forward sooner than ours. We tried to frontload this in the summer, so that we could potentially impact their work.

I will also go ahead and tell you that we also have two real subject matter expert speakers joining us today, Steve Eichner from the Texas Department of State Health Services and Nedra Garrett from the CDC, both of whom have been very involved in addressing public health needs regarding interoperability. We will allow them to introduce themselves briefly in a moment before they make their presentations. Carolyn and Janet, I wanted to give you guys a chance to introduce yourselves and say a little bit about the work of the task force that you are leading. Carolyn, do you want to start off?

Carolyn Petersen
Thanks Steven, sure. I am Carolyn Petersen. This is my fourth year as a member of the HITAC. I started when it was formed back in 2018. As Steven mentioned, Janet and I are co-leading the Public Health Data Systems Task Force. We are tasked at coming up with some recommendations for ONC and CDC leadership, to look at and bring forward to discussions undertaken at the HHS level. We have had some discussions about various lab related topics and some other things at previous meetings, that are held Thursday mornings, from 10:32 to noon Eastern time. We have started discussing the recommendations, our draft recommendations, and trying to finalize those with an eye toward revving up those recommendations on July 8, so that we can present them to the full HITAC on July 14th, and from there transmit them to the national coordinator. With that, I will pass the mic to Janet for her introduction.

Janet Hamilton
Great. Thank you so much. It is wonderful to join you all this morning. I am Janet Hamilton, and I am one of the cochairs. I represent, in my day job, the Council of State and Territorial Epidemiologists, where I serve as the executive director. Prior to joining CSTE, which is a nonprofit organization that supports epidemiologist working at the state, local, tribal, and territorial levels, I worked in a health department overseeing surveillance activities for about 15 years. I will just add on, that while our group is maybe going to be making recommendations prior to this one, the data elements themselves play a huge role in public health surveillance. We are very interested in listening to this conversation, so that we can align maybe our more overarching comments and recommendations with the specifics about the data that is collected. We have had several conversations specifically around the improvements in our public health work that support diversity, equity, and inclusion, and of course the disparities. The work you all are doing is core to the
broader public health surveillance picture. I thank you very much for the time and look forward to the discussion today.

**Steven Lane**

Thank you both for your introductions and for joining us today. I also wanted to say that we have a number of members of the public who were listening and today. You are all encouraged to take advantage of both the public chat in the Adobe meeting, as well as the time that we dedicated at the end of our agenda for oral public comments. As you are listing, if you have something to share at the end, that would be wonderful. Thank you again to the other members of the task force who have joined us a little late. We just now getting started with final introductions. With that, Leslie, did you have anything you wanted to add before we let Steve and Nedra take over?

**Leslie Kelly Hall**

Yes, I just wanted to thank the group for their service this last year. All of us have had a crazed year, but they work that you have done at CDC and all the areas each of you represent, has been tremendous under scrutiny and pressure. I just wanted to say thank you.

**Steven Lane**

Here, here. With that we are going to invite Steve Eichner and Nedra Garrett to make some presentations. Maybe let us go to the next slide if we can. Thank you. These are their titles and maybe, Steve, do you want to introduce yourself and go ahead and give your presentation? Then we will ask Nedra to do the same.

**Steve Eichner**

Sure, absolutely. Absolutely. Is my audio coming over well?

**Steven Lane**

Perfect.

**Public Health Agency Recommendations on ONC USCDI Priorities (00:10:40)**

**Steve Eichner**

Great. Well, good morning and thank you so much for having me. My name is Steve Eichner, and I currently serve as the Health Information Technology Lead at the Texas Department of State Health Services. I have been working with DSHS for about 15 years, with a focus on data interoperability and program coordination. First working in behavioral health and then expanding my role to address departmentwide needs. I am actively involved in HL7 workgroups, involved in state data standards, serve as the cochair for the [inaudible] [00:11:19] interoperability task force, serve as a member of the Public Health Interoperability Task Force for Janet Hamilton and Carolyn, and OSDH and a lot of other really interesting activities around data exchange, and really advancing how public health can work with partners through the [inaudible] [00:11:41] and providers, to improve how we collect data and return data in useful formats for both professional, personal, and community level uses. Let us go to the next slide please. Next slide please.

What I wanted to do first was a little bit of level setting from the common definition of what is public health. This definition is from the CDC foundation. Public health is the science of protecting and improving the health of people and their communities, with a focus on promoting healthy lifestyles. Including: addressing
chronic conditions, both in terms of helping avoid chronic conditions from developing and managing them if they occur, researching disease and injury prevention, which we often do in partnership with other organizations such as the Department of Transportation, and detecting, preventing, and responding to infectious disease. One need not look too far in history to look at the goal public health has served in responding to COVID 19. In sum, public health is concerned with protecting the health of entire populations. We may do that, both at community level actions, as well as providing integral healthcare in certain situations, particularly near highly infectious diseases.

The Texas Department of State Health Services for example, operates the Texas Center for Infectious Disease, which is one of the nation's few centers focused solely on the inpatient care for significantly infectious disease. Next slide please. Next slide. Oh Sorry.

There are 10 essential public health services that really define how public health delivers services. First will be assessing and monitoring population health. Looking at investigating, diagnosing, and addressing health problems and hazards that affect the population. To [inaudible] [00:13:55] effectively. To strengthen, support, and mobilized communities and partnerships to improve health. Create and champion policies, plans, and laws that impact health. Utilize regulatory frameworks to improve and protect the public's health. Assure an effective system that enables equitable access to health care and health services. Build and support a diverse work force to deliver public health services. Improve and innovate public health functions to ongoing evaluation and improvements. Build and maintain a strong organizational infrastructure for public health. Not all of these are not all directly related to data interoperability, but many of them are. We are going to drill down a little bit further in this next slide please.

Data becomes very important to public health in our ability to access and monitor population health status. In fact, [inaudible] [00:14:55]. It is critical in investigating, diagnosing, and addressing health problems, as well is helping drive public health system improvement. We need that data to strengthen and improve community health population. We need the right systems in place to use that data and improve our services, to constantly improve our ability to deliver significant health services and share data with healthcare providers and other entities that use that data, both for care and for decision-making. Next slide please.

Data standards and interoperability really do help advance data exchange with public health. The use of standards, such as those in the USCDI, reduce costs for providers in public health by reducing the need for customization of systems, rather than having all providers in the state of Texas or the state of Rhode Island have to modify their systems to meet the standards required for each state. Using national level standards facilitates a single method of implementation, to support a very diverse set of local state and state governments in public health activities. It reduces administrative time to complete reporting by using standardized messaging and standardize data sets. It becomes easier for providers to automate the change of data with public health. That reduces the administrative burden of having to fill out papers by hand, faxing them in, and am waiting for a response.

The ability to have systems talk to each other, using standards both for the data and standard transmission standards, enable the automated exchange of data, which greatly facilitates public health stability to get data in a timely manner. This critical when responding to highly infectious and emerging diseases and reduces provider time and cost for supplying that data. It also supports increased frequency of data collection without increased costs. Once the base network and the base connectivity is established, it does
not really matter how often the data submitted. It can be automatically collected whenever it is needed without impacting those costs. It also facilitates data aggregation and comparison across jurisdictions. Without data standards it would be difficult for the CDC to collect data from the states, assemble that to understand a nationwide situation, and enable Congress and other policymakers to make informed decisions at the national level.

Same thing occurs at the state level. If different data were collected across different jurisdictions within the state, state leadership would be in a difficult position to use data to make informed statewide decisions. Those are critical, because it is very efficient to develop programs and services at a statewide level, focused on the delivery to particular communities. Again, they want to be data driven wherever possible, because that is a way of improving services. Next slide please.

Looking at some of the areas that public health collects data in, that uses the data standards, including those in the USCDI, are things like: Immunization registries, which have certainly been in the news recently, supporting the delivery of COVID 19 vaccines. Investigation into maternal mortality, to better understand what happens in a situation where a mother dies near birth, to improve care delivery and services to avoid that in the future. Looking at things like birth defects, registries, and aftercare. That information is critical, because early intervention for a number of diseases can substantially reduce the cost of care for infants. Things like cancer registries also use data standards to collect data, not only for coordinating individual care, but to build data resources to support cancer research and investigation. The Texas Department of Health Services works extensively with a number of parties, including the Cancer Foundation in Texas, to support research.

Syndromic surveillance is another system that you probably have heard of fairly recently, that collects data from hospitals as patients are admitted or discharged to emergency departments. That serves as an early warning system, or an early detection system, for public health to be informed when there is an unknown situation in the community that we can task it early on and be able to build a response more quickly. Things like electronic case reporting and electronic lab reporting, are two methods that public health uses to get information from ambulatory providers as well as hospitals, about actual test results. Those test results can help inform where there is disease emergence, and what response may be necessary. And of course, things like vital events, which include birth events and death events, is also something that is collected by public health and shared with a variety of other governmental entities and resources.

In many cases, public health also provides laboratory services. We rely on data standards for exchanging that data, making it easy for providers to submit orders and samples to public health, and easy access for providers to retrieve test results from public health laboratory systems, to improve delivery of care to their individual patients. Next slide please.

Now, there are some areas I think we need to work on to improve the USCDI, obtain exchange guides to benefit public health, and support of the coordination between public health and providers. One of the things that public health has noticed over the years, is that there needs to be clarity and guidance about whether an element included in the USCDI, and that included in an electronic health record product, the optional or required by public health.
What we found is that quite often, if it is listed as optional, it is not actually implemented and supported. What public health usually means by the word optional, is that if you have the data, you should report it. Not it is optional to have a system to support the data. That is something I think we can work on, clarifying those implementation guides, and potential companion guides to the USCDI. Looking at coordinated review by state and local health experts as well as the CDC, in looking at data elements and classes submitted for consideration to the USCDI, as part of the USCDI improvement process. There are a number of folks in public health that would be very interested, and could probably make themselves available in some capacity, for reviewing elements of USCDI to help prioritize and understand the value of a class or a data element, as to how it benefits public health. Even going beyond something that may have been submitted by one health department in one jurisdiction.

I think there are also some opportunities to prioritize elements and classes, recommended by public health related organizations. One of the challenges for public health, is that we tend to have a long implementation plan, or long implementation schedule. Texas, for example, runs on a biannual budget. We have just completed our legislative session with new funding starting September 2021. The next legislative cycle is not for two full years, with the next available state funding coming available in 2023. That is a very long planning cycle for us to begin procuring things in 2023, for implementation for things in 2024 and 2025. We really do look at that lengthy schedule for implementation, because of approvals that are required to implement projects and secure appropriate funding. I think there is a lot of opportunity, we are very appreciative of all of the work that has gone into the development of the USCDI.

One thing that is a little different about public health’s utilization of the USCDI as it stands, is that much of the data we use does not come out of a single class. We may very well be looking at data from different classes, things like demographics, or a disease, or immunization, or lots of other things. One of the things we are interested in doing perhaps, is looking at how can we partner and develop companion guides to help explain the USCDI data elements, in terms of the implementation guides for public health reporting and data exchange. Whether it be through HL7 messaging or FHIR. At this point, I would like to turn the floor over to Nedra for her presentation. Or should we stop and have questions?

**Steven Lane**
We have a couple of questions Steve. Thank you very much. We really appreciate your presentation, and specifically the way that you focused in on recommendations that our task force might consider. Did you want to speak to your slide nine in particular? I will go back up on slide there.

**Steve Eichner**
Yes, thank you. As I just mentioned, reviewing implementation timelines to help create a framework that is effective for all parties. If the data is to be reported to public health, it may not be practical for healthcare providers to implement those standards prior to public health being able to receive them. The same thing can occur in the other direction. If providers are driving for change in data standards, if there is a change, or public health required to receive the data in a different standard, there needs to be collaboration in that sense in that part as well, when looking at implementation plans, and the implementation schedules do need to reflect that. This is because we would love to be able to exchange into practice as soon as possible, rather than having the adopted data standard that is sitting on a shelf ready to be used but is not used for an extended period because there is no available technology.
It would also be helpful if additional guidance or maturity were considered but not included regarding standards. For instance, looking at what does it take to get a standard that may have been suggested for the USCDI, but not included in this round, into the next round. That we can better understand where the goalposts may be for adoption standards. Whether we are looking at number of providers or number of states. Whether we are looking at the metrics to help identify what is necessary to bring things into play. Finally, looking at clarification around the APIs, and how treatable of data classes and elements must be supported. In other words, looking at support for the repulling the entirety of the USCDI in a singular pull, or whether individual elements, or individual classes may be pulled through an API [inaudible] [00:28:11].

**Steven Lane**
Great. Thank you, Steve.

**Steve Eichner**
Thank you very much [inaudible] [00:28:15] points. Now if you have questions, I will be happy to answer them.

**Leslie Kelly Hall**
I think we have a few. One from Andy, and Mark has one in the chat. I have one as well. Why do not we start with Andy?

**Steven Lane**
I am sorry. I just wanted to make an overall observation, which I think will set up Mark's comment. Steve, what I note, is that your presentation focuses understandably on unidirectional flow and primarily push of data, from providers to public health. Which of course is the long history of public health reporting. Then also with case investigation, querying that may occur from public health to providers to submit additional data. One thing that has come up, in both this task force and the Public Health Data System Task Force, is the desirability to think of the data flow is being more bidirectional. To think about an ecosystem of collaboration between public health professionals and providers. I do not sense that in what you said, except in that last bullet you had about API retrieval of classes and elements. There, I think what you are saying is, the public health system querying a provider to be able to able to retrieve classes and elements. But I really do hope that we, as we think about USCDI and its role to support public health interoperability, that we are thinking about by directionality. Providers could be querying public health, potentially patients could be querying public health, other stakeholders getting data from public health, public health not simply being a black hole that data goes into and never comes back out of. As a provider, I think about how much benefit I could derive, and my colleagues could derive, from more direction from public health, more information. Whether it is about antibiotic sensitivity, recommended treatment, follow up, et cetera, as we are caring for patients with reportable diseases and other conditions. Certainly, when we think about chronic disease in a population, what are recommendations that are coming from public health within a given jurisdiction?

Mark Savage threw out a question. Does public health need write access APIs, as well as read access? There again, presuming that there is data from public health, that they would then be writing back to the systems of clinicians to help guide their care, potentially using CDS hooks, et cetera. I wanted to open up
that as part of our broader discussion, not ahead of Andy’s or Mark’s comments. I wanted to put that out there. Now Andy, please throw out your idea and Steve, we will give you a chance to respond to that later.

**Andrew Truscott**

It seems like you claimed imminent domain on the questions Steve. I will comment on your point there. When I think of this, I do not think of it in terms of directionality, so much as closed loop. Getting the feedback from public health to better inform direct treatment and treatment of populations, that is very important. I agree entirely. But I do not see that as being a synchronous bidirectionality to messaging and information that is being sent into public health from [inaudible] [00:32:06]. Does that make sense?

**Steve Eichner**

Yes. Let me drill down on several examples of current status. Immunization data, the initial standard under meaningful use, was for submission only. The 2015 standard includes support for bidirectional exchange as part of the data standard, and almost all states have upgraded their immunization systems to support bidirectional data exchange. Whereby a provider that is registered within the system can query the IAS system at the state level, for a particular patient’s immunization history. The system also provides computer [inaudible] [00:33:02] support in the form of a vaccine forecast, based on standardized vaccination schedules. Currently, that is [inaudible - crosstalk] [00:33:12] that is one example. Looking at things like our laboratory services, we have had for a number of years different capacities for receiving messages or receiving test orders electronically. Some states, some jurisdictions may still be using a web interface base where providers can type things in.

We got some services in Texas that are using HL7 for lab orders and test results. We have got a project going on with five hospitals, specifically focused on newborn screening to increase the number of newborn screening test order results that we received electronically, by something like 125,000 a year. As another example, we are looking at improving our birth defects and follow-on care perspective, to support better data exchange with providers, and coordinated care for individuals that are saving support for birth defects through the state. We also have a regular history of exchanging data with Medicaid in Texas. He pushed some data through our Medicaid services. By no means is that an answer completely and we are done. But there is a foundation on which we can build to provide more data.

**Steven Lane**

You missed the ECR reportability response in there, which is another example.

**Steve Eichner**

Yeah, so there are lots of things.

**Andrew Truscott**

I was trying to draw a difference between submission and retrieval, which I think we do have some very fundamental capabilities which expand across the nation. But also, to where Steve Lane was talking around the idea of actually getting guidance out to the point of care that is based upon whole population analytics, et cetera. That is where I was going. That is just responding to Steve’s point. My actual question was around the timelines for implementation. You outlined, Steve Eichner, in comments, and I took them as meaning the time frames need to be compressed. Though, I would like a little bit of insight from yourself and maybe from other colleagues in public health on the line, about your desires, aspirations, preferences maybe,
around what timelines make sense to you? What timelines do you think the public health can pivot to, to adopt additional capabilities, which are stimulated through USCDI, or not? What would your aspiration here be?

**Steve Eichner**

Thank you for the question. I think some of the challenges, public health would love to be as modern as possible as fast as possible. Unfortunately, like many things, there is resource constraints that may limit our ability to react as quickly as we might like to. Each state has its own approach to funding public health and its own legislative challenges. Texas as I mentioned works on a biannual schedule. There are other states that operate on an annual schedule, where they do a budget annually, and more policy discussions every two years.

Some states have both policy and budget decisions every year. Where that becomes challenging, is that we cannot implement a project to make significant changes to a system, without legislative approval and funding. We need to figure out how we transition from where we are, in terms of funding cycles and the emergence of a new data standard, to a different approach perhaps. That says, “Okay, the legislature realizes that this specific standard may not be identified today, but they know that it is coming and scheduled to be delivered in 18 months and are willing to fund implementation of that data standard when it becomes available.” If that makes sense to you. [Inaudible - crosstalk] [00:37:59].

**Andrew Truscott**

Okay. Thank you, sir.

**Steven Lane**

Yes Jim. Jim where you saying something?

**Leslie Kelly Hall**

This is Leslie. You brought up two points that I would like to emphasize. One was the repurposing of existing standards to benefit public health, this is something that Clem has constantly reminded us of. I think that would be an area for public health to demonstrate some influence collectively, to help inform that bias as an existing way to leverage very narrow resources and public health settings. I encourage you to do that. Another point you brought up is something that we have not heard before. You said that the public health might be picking up data elements from several different classes, and it creates its own need or its own class.

I wonder if maybe in your task force, or you have started to think about data classes that are more across multiple classes that benefit public health. I mention this because we look at individual items within the data class, to serve right now, under the eyes of mostly as a provider environment. It might mean that we are picking and choosing elements that get to 50% of what is needed in public health but having elevated knowledge that says these items across multiple classes could form a totally new class for public health. I wondered if that had been considered in your task force, or brought forward in recommendations elsewhere?

**Steve Eichner**
Thank you very much for the question. It is excellent. One of the things that we have talked about in the Public Health Task Force, was looking at the development of what we labeled companion guides for lack of a better designator. The vision for that was looking at a crosswalk of what the public health need is, looking at selecting or identifying the class and the data element. If you were to focus solely on a public health lens, you might really reorganize an existing class structure with that as a focus. That might not be practical for associating different elements from a usage perspective. If we were to develop companion guides, that does not necessarily have to be restricted to public health, but the idea of saying, “Okay, here is the activity that I am trying to accomplish. Here is my business need for doing this. What are the data elements I need to accomplish this goal?”

Whether it be a case report for contagious disease, or a birth defects investigation, or registration, or a maternal mortality review. Each of those concepts, are going to have a lot of data out of things like demographics, and a scattering of fields from other places. But if you assemble this structure as a companion guide, we can then highlight those elements. It will not do it justice from a public health perspective, but if you are looking at other kind of interventions and other things in space, then that might also very much apply. [inaudible] [00:41:58] social services as another care, if you are looking at integrating SGLH data to improve childcare or child education. There is a lot of opportunity to look at. I think the USCDI is the core data set for what data we are acting on. Something like the companion guide approach is describing how are we using this data, or what is needed in a specific healthcare delivery problem. If that makes sense.

**Steven Lane**

That makes sense Steve. Thanks so much. We have another question from Clem, and then we want to switch over to Nedra’s presentation. Clem?

**Clement McDonald**

Lenert’s idea, that what we really should be working toward is using the initiated network, so that all of that overhead of connecting goes away. That could be huge for the public health world and all the communications. Secondly, instead of thinking about forms you ask physicians to fill out, and then different departments ask for different questions about the same things. These things may be hard for the clinicians to answer because they were not involved in the question, and public health does not always know what is available. Whether they could just query the medical record systems to pull the data that is needed, and they could get it always and quickly. It is complicated, but I think that should be given a lot of thought, because it would take away the burden, and improve the speed and completeness of data. Thank you.

**Steven Lane**

Absolutely. Thank you for that comment Clem.

**Steve Eichner**

I do think there is one challenge in public health pulling data, as opposed to a query being initiated at the local level. There are some hybrids looking at things like MedMore, which is a distributed query system where the query may be developed by a public health or another entity but is actually hosted effectively in the providers EHR. The decision about what is reported if you will, is made in the local EHR. Public health does not necessarily know where all the data it is interested in resides. We do not necessarily know what providers may be giving an immunization for example.
**Unknown Speaker**
Well [inaudible - crosstalk] [00:44:42].

**Steve Eichner**
[inaudible] [00:44:45] if we know that somebody is giving immunizations. But if you do not know they are giving immunizations if you do not know to look.

**Clement McDonald**
I can see that is a problem. But I think that can be fixed by the public health being able to reach in and pull what they wanted.

**Steven Lane**
Especially if we have data standards to support it.

**Clement McDonald**
Exactly.

**Steve Eichner**
The other key piece, as I mentioned, is figuring out who has the relevant data.

**Clement McDonald**
The idea would be pull them along and find out, but there is a lot of stuff between here and there.

**Steve Eichner**
Looking at immunization delivery, vaccine delivery with COVID 19, there were a number of nontraditional providers that began giving vaccines for COVID 19, to help people get vaccinated faster and more efficiently. That is wonderful. The difficulty from a data perspective, is that many of these entities that were newly giving vaccines, did not have a previous relationship or previous connectivity with public health to report data. Without a previous connection, there was no ability for public health to connect with them to pull data out. I think companion piece to what you are suggesting might be a registration system by providers, to help identify what data they are collecting, and what services are providing.

**Steven Lane**
Great. Thank you. I want to move on to Nedra's presentation, and then we will be able to open it up more broadly.

**Steve Eichner**
Thank you so much.

**Steven Lane**
Thank you, Steve. Nedra?

**Nedra Garrett**
Good morning everyone. Thanks Steve, for a great presentation and setting the stage for some of the work that we have been doing around the CDC. I am Nedra Garrett, as you know. I am the Senior Informatics Health Scientist within the Center for Surveillance, Epidemiology and Laboratory Services. I am also an informatics team lead within the health care data session, working in the response for the last year. Basically, I am doing a day job and a response job. Today I want to talk to you about some of the work that we did around coordinating our USCDI submissions. I really appreciate the opportunity to present this to you. Today, I am going to discuss the process that we used to identify some of the priorities, public health data elements, and provide a few recommendations. We recognize this effort as critical, that we participate in an organized way, and advocate for data elements that can support CDC programs for routine surveillance, but also to advocate for those that can support a response. As you know, CDC has a lot of data systems, we have a lot of surveys.

I think the last count a couple of years ago was 120, there may be more now. Hopefully not too many more. It is important that we are able to leverage the data in its source format, to be able to reduce [inaudible], and then to reduce the variability of data in our public health system. For CDC, our goals around USCDI are to improve the [inaudible] quality of use of public data, to be able to align our public health data with national standards, to promote and harmonize the data elements across CDC systems, to leverage any existing CDC efforts and engagements that we have to identify these priorities, and then to develop or enhance any tools to promote the use of these standards. Next slide.

So, the process. Clinical and public health priority data elements are coordinated and prioritized across CDC programs. We were able to take advantage of some of our earlier data harmonization efforts that we did around pregnancy status during our Zika response and travel history. We worked very closely with CSC on that. We learned about diversity of data within travel history. In that instance, we were able to reduce the 80 or so travel questions down to 18, to a small template of data elements within that. Also, as part of this process we worked with Georgia Tech Research Institute (GTRI) to help us categorize the most frequently used data elements across different systems. I will discuss more of that on the next slide. We also worked closely with Steve and his group Public Health Interoperability Task Force and ONC, as we sought clarity on the process, and addressing issues around things like the appropriateness of merging certain data elements. Next slide please.

We brought together program representatives that include those with informatics and data centers expertise, to identify some of their high priority [inaudible] datum elements. In a system that we worked with GTRI, we were able to leverage machine learning tools to help identify those that were frequent, and we were able to categorize those as well. That helped us to provide some of the evidence for the use cases, that we provided on the different data elements that were submitted.

We also vetted the work with CSTE and the task force. We were able to get some input on different things. We had some examples of the high frequency data elements included, such as work history, practicing symptoms, and others, of course. But the machine learning activity coincided very well and was very consistent with our priorities identified by the program. That was a different way in which we were able to help support our submission. In terms of our submission, we submitted 106 data elements. A large number of them were duplicates, many other people were thinking the same. There were 77 that were duplicates, then 18 of them were accepted and published. Next slide.
These priority data elements listed here were classified and published by ONC during this year’s USCDI version two submission cycle. We did have six that there were classified as a level two, which we hope we can move forward in the version three submission cycle. We recognize that level one and level two are based on maturity and the value in the implementation earned, and that ONC has to further prioritize those level two data elements down even further, which will reduce the actual number that were able to be accepted. Next slide please.

Here are some examples of some other priority data classes and elements that we believe are really important. As I mentioned, with pregnancy status, that was an earlier work that we did where we convened a number of different programs across CDC, and basically distilling pregnancy status down to discrete data elements. There was a guide that was developed from that work, but I do not know how well adopted or used it is at this point. We do want to continue to advocate for pregnancy status, as it is really important for us, [inaudible] [00:53:52] responses as it were in Zika. I do not think we have to make much of a case for that. Another example is the patient work history. That is one where my colleagues in NIOSH have been working diligently for years, in trying to advocate for occupational data for health. There were a number of different submissions around patient work, that we put forth. Around things like current occupation, current industry, employment status, and others. Then others around the specimen type, collection date, and travel history.

Obviously, there is a lot of focus right now on social determinants of health and health equity. We want to continue to advocate for those data. We are working closely with Gravity. We have people that participating in the accelerator, in trying to keep a handle and track on both data that are standardized coming out of there. That has been on our radar. One that I do not have on there is around device setting. That was an important one for hospital reporting, the device settings, and the delivery route that we sought further clarification from OSC on. The relationship has been good in helping us to be able to gain that clarity and try to advocate instruments in our submissions. Next one.

In terms of the recommendations and next steps, as Steve mentioned, in terms of the big picture, the whole goal is to improve reporting to public health. We are recommending that we consider expanding the number of accepted data elements if possible. Only the nine were prioritized, and obviously many of them that we submitted did not get included but are available there for later consideration. We do not know what our use number is. I do certainly believe that 106 is not a reasonable number, but our submission represented the whole of CDC. There were programs from chronic infectious disease, immunization, the whole plethora of conditions. That submission reflected perspectives from all of them. Is there way to increase the number for this cycle, for review and adoption in subsequent versions? We do plan to continue to build upon our current submissions to strengthen those use cases where we need to, and to continue to monitor standards and IGs, so that we can move toward reducing variability where possible.

The good thing is ONDEC is available to us now, we can use the system and continue to build upon that. I think there were a few hiccups along the way, but overall, that is very positive for us. We have to identify where the opportunities are to align with those data elements that is already been standardized. We need to look at those similarities, and determine the data that we actually need, and determine if that data might exist already. In some instances, it does. Most of the data elements are clinical in nature, and likely more available in an electronic health worker, than the more public health-oriented data cases. The support case investigation exposures and so forth. We should leverage the USCDI to the greatest extent, to improve the
collection and use of these data. As I mentioned, we have over 120 different surveillance systems. That is not an easy feat but is something that we need to think about how we can better use and align these data.

Then we need to continue to promote these standards through CDC Standards Management and Data Harmonization Workgroup that we are sending up. This workgroup will provide governance and direction and help convene groups for prioritizing data elements. Also, it will facilitate some tooling that may be necessary. This will help to promote the adoption within CDC programs. We have funding through our data modernization initiative that we are using to send this program up. We are also using, as part of DMI, we have funding to support real-world testing for FHIR solutions. We are thinking of focusing on Bulk FHIR now, but we do recognize the importance and value of USCDI and moving more towards FHIR based solutions. We will continue to work with GTRI on transition in the machine learning tool, that they have developed for us with this particular work, for future uses. We will continue to be able use that, to look at the frequency and begin to categorize that information, to support and strengthen our use cases.

Lastly, we will continue to engage CDC programs and public health partners on our submissions, advocate for inclusion, and work with ONC on any issues and priorities. I believe we have the infrastructure to engage, to prioritize, and documents that evidence. We have people that are willing to engage to get public health accounted for in the process. We have taken on the work within our DMI work. We built in work for pilots for very various solutions that leverage [inaudible] [01:00:40] and USCDI. We have done extensive work in pulling all of this together. I can share that document with you where we have all the data classes, elements, use cases, standards, everything that the ONC has asked us for. We have compiled all of that and want to continue to leverage that going forward. That concludes my presentation. Thank you for the opportunity to present on our CDC - USCDI activities.

Steven Lane
Thank you so much, Nedra. We really appreciate all the work that you and the team have done to pull this together. I know you and I have been talking about this for the better part of the last year. It is great to have you come and present it. You mentioned on your slide three, that there were 77 duplicates. That is to say that your group identified data elements that had already been submitted to ONDEC. Did you take the opportunity to add comments to some or all of those? Clarifying your support, adding detail, and input to the prior submissions? Or did you simply note that they were already there and move on to focus on the new ones?

Nedra Garrett
We actually did provide information on the use cases, the public health cases for those. Some of the duplicates were around the work history, [inaudible] [01:02:23] around the patient demographics. There were a couple that were merged. There were duplicates around the pregnancy status and encounter. Encounter, obviously you are going to have a lot on that. For all of those, we did provide our comments on them, though they were duplicates.

Steven Lane
I think that is great. I think it goes to Steve’s earlier recommendation, regarding supporting review by state and local public health subject matter experts. And I think that this is really key in the USCDI process, that we encourage the participation, review, and commentary by subject matter experts. Whether they are coming from CDC or states and locals. That is great that you did that. The other thing on your slide four,
where you clarify of the high priority data elements, where they have been leveled in the USCDI process thus far, I think it is important for all of us to realize that leveling was done for the V2 submission cycle. We are anticipating as we formally kick off the V3 submission cycle, that there may be a reevaluation or a relveling of the various items that are already in the USCDI. Those that were level one and have now been shown to warrant being at level two, should be identified as such. I think it is going to be exciting.

I will be curious to see, and Al maybe you can comment, whether the relveling process will occur as part of next month's big event, the formal opening of the V3 cycle and the publication of V2, or whether that relveling is going to occur somewhere further down the line. Clearly so much input has been provided. Al, maybe you can comment on that, and the question that I sent to you. Comment on what would be the most valuable thing for our task force to offer now, to supplement or support the input that ONC has already received from the public health community.

Al Taylor
Thanks Steven. Regarding the possibility of re-leveling, moving things up to level one or level two, we are always open to that. We have had a few conversations about whether or not certain submission should be leveled up. In some cases, they have been, and at least we have agreed to relook at it, and it looks like there might be some movement. I think one of the questions that we have not made clear, is that one of the criteria for leveling has to do with the breath of applicability of a particular data element. If the submitted data element is highly granular, meaning that it is a very specific data element that could not apply to any other situation except for that one particular thing, it is generally merged. Merged and duplicate are the same bucket in the ONDEC process. We did a certain amount of lumping in the process. A lot of the granular data elements, both from the CDC submission and many others, fell into that category of granular that could be included in another data element or data class.

I think that because we want USCDI to serve the broad community, I think that focusing on the particular use. The public health reporting and investigation use cases, are an important thing to look at as far as an area where we could prioritize, and if those data elements are unique to those data that are normally collected only in the routine clinical care use case, or the data elements that are used for patient access. That is something that we can look at whether we will branch out into other use case areas besides straight patient care. Where the data elements are similar or the same, but they are used in both public health and in clinical care, like lab results. Obviously, there are certain elements of a lab result, that are important for public health reporting. Some of the meta data around specimen and the like, that may or may not be as applicable to direct patient care or the patient may not need to know that information about a specimen, that is something that we would look at. That would be an expansion of the use cases that go into including new data elements.

It is something that we can look at. I cannot really say where the direction ONC is going to be turning or looking towards expanding into. I do not have that information right now. We have not really settled on it yet. But we are certainly open to hearing from Nedra, Steve, and other public health. We are also going to hear from people in other areas representing other use cases for us to consider. Like are we going to focus on, or are we going to look harder, at some of these other use cases?

Steven Lane
Thanks. Leslie, did you want to chime in?
Leslie Kelly Hall
I did. This is a question for Nedra. You talked about how the submission from CDC was from the entirety of CDC. I wondered if CDC had done prioritization themselves. We heard from Steven in his presentation, how considerations for prioritization as well as maturity, were important. In our last submission to HITAC, we talked about priorities as well as maturity. Knowing priorities is very helpful. Has CDC, or will CDC prioritize data classes within its entirety?

Nedra Garrett
Yeah, we will. In fact, we try to be really coordinated in our response, so that we are not so fractured. We may have had a couple of programs to submit in USCDI separate from this. But I think I will continue to speak to the fact that, it is not going to help just to keep putting it in three or four the same thing. We just need to get the one right, right? We tried to emphasize that. I think we have a really good process of engaging the different programs and identifying those priorities. For example, I had mentioned the device setting and delivery routes. In HSN, obviously during COVID, had a critical need for the device setting and delivery route for mechanically ventilated patients, and then isolation precaution orders. That was a leveled as a comment. I worked with the program, and they would ask the question, “Did we not provide enough justifications? We recognize that this is critical. We know that CERNA has the ability to do this. There are two existing FHIR resources to support it. What more do we need to do to get it in?” Trying to have those conversations with ONC is a priority because we are in COVID. It is a priority generally, but it is really a priority because we are in COVID. Is that a factor in any of the leveling considerations? Those are things that we probably need to discuss and see if that has any influence at all on any of the prioritization. I know that the timelines for these would be beyond the immediate response that we are in. It is likely to be an issue for a little while.

Leslie Kelly Hall
Thank you. I think we have two questions. Clem and then Hans.

Clement McDonald
I have a number of questions and comments. First, hearing there is 120 surveillance systems, I would think that would be immediately a signal to get rid of a bunch of them. That just does not make sense, all that redundancy. That is going to kill public health everything, unless there is a coherent unification across. I sense from your discussion, that you are sensitive to that, so I do not want to harp on it. But we got to stop the multiplicity to make this all work. Then a couple of stuff. There are two slides. You had one slide with specific variables, it seemed very reasonable. Then in another slide was monstrous questions about work history. That is a half hour, forty-five minutes, two-hour data collection effort, and it is not most relevant to most clinical visits. One has to be conscious of the difference between what public health might like to have, because it is there, versus what we really would force clinicians to collect.

The same with travel history. For the first three months of COVID, everybody asked about going to China, but no one asked after. We have to be conscious of the difference in the scope in the work effort. In practice, clinicians ask these conditional. Someone comes in with shaking chills, and they are a having [inaudible] [01:13:46], they will ask about travel. But they are not going to do an intimate travel history on every single
patient that comes in the door, so just be aware of that. Pregnancy status is a good bet, but of course it only applies to women.

The specimen type is [inaudible] [01:14:00], because 99% of all test results come in with a specimen in the name. Maybe 98%. CDC has resisted using those combinations, and instead wants to use a specimen segment. We heard from the epidemiology group, that it is hardly ever delivered, but it is hardly ever necessary. We ought to condition that, you want to have the specimen segment when it is a culture specimen or something narrower, to make this easier for the clinical world and the public health world to live together. Sorry. Those are just some comments on the process.

Leslie Kelly Hall
In terms of the system, we know that is a problem. This is why we tried to do this public health data modernization initiative, to reduce that and to reduce the variability in our data. We asked many questions that in different ways are getting at the same response. We recognize that it is a real problem that we are working on. In terms of the laboratory specimen items, I think that this is why it is important to bring out the right people to the table, to really understand what our real data needs are. What is the real question we want to answer? What exactly is required? [Inaudible] [01:15:30]? What is really available? All of those questions need to be brought to the table to discuss any of these that are questionable in the electronic health record or requiring additional engagement and documentation. These are the kinds of questions that we would bring to the table to figure out what it is that we really need.

Steven Lane
[Inaudible - crosstalk] [01:15:57]. Sorry Clem, go ahead.

Clement McDonald
I just wanted to add [inaudible] [01:16:02] all that. That is really what we need to make this all work. Thank you.

Steven Lane
I was going to follow on, Nedra, I wonder in your relationship with the team at GTRI, whether you might ask them to address Clem's question? With their machine learning tools, they could go in and help figure out how often that test name is included in the specimen type, or the source in it. And help to identify where there is missing data. What proportion of specimens would there really be a need to collect that additional segment? As Clem said, narrowing it down to minimize the burden, since it sounds like that is an ongoing point of contention.

Nedra Garrett
That is a good point and good suggestion. The whole point of the tools would be to help us in identifying where it is used, and how often. Or if it is not there. I will take that as a follow-up.

Steven Lane
Hans? You have a comment? Question?

Hans Buitendijk
I do. Nedra, how are you doing?
Hi Hans.

The question that I have, is around the scope of USCDI, the progression of it, and the data that you have started to identify that is relevant and of need to gather. A lot of the data clearly that you have described is considered electronic health information, and logical candidates for the USCDI to be included as some version as we progress. Sooner, later, whatever that might fall out to be. Also, some examples of where the data is of interest to public health is perhaps not. Or it is grey, whether it is part of electronic health information, or it is not. Two examples. One we can obviously argue because it is in the grey zone. The “not” is operational surveillance data, that contributes to that overall picture. The other one is that if you get into device settings for certain detailed data, that may not be considered electronic health information depending on the definition that you use.

Have you been able to identify data that is not or might not be EHI, therefore not necessarily part of USCDI? That we still need to be concerned that we get a consensus around how to collect it and how to gather it, because it might not fall under the progression of USCDI expansion.

Right, that is something that we have not looked at that in a focused way. It is something that we are considering. I think you are getting more into public health data that we need, that might be outside of electronic health records in a standardized format. As you know, in public health, we have a lot of different information that is coming in as discrete data, as well as questions and answers. We are looking at ways in which we might be able to use questionnaires. Obviously, we are starting to look at some of Clem's work on that, but to look at FHIR solutions for getting some of that information. There are some data that we probably [inaudible] [01:19:28], and then there are some that we need to scope based on the need and getting that which we absolutely need. We are looking at different ways and different options for people to do that. That is part of the data modernization initiative work as well and being able to test some things out.

Perhaps to clarify, it is not as much whether it is or is not in the EHR, it is more about is it data that is considered electronic health information. EHR, we have information that is not considered electronic health information, yet it is of interest to public health. They are two slightly different things there.

Hans, I think you are making an assumption, that I would like Al to comment on, that only data that falls within the current ONC definition of EHI would be appropriate for inclusion in USCDI. We spoke last week with the folks from the ISP task force about operational data, about readiness data, capacity data, as potential areas into which USCDI might expand. But those things as you say, do not meet the definition of the HI, they are not part of the individual patient’s designated record set. I wonder Al if you could comment on that?
I think an important thing to remember is that USCDI is core patient data. That definition of core can maybe change over time. I cannot say without looking at an individual item for consideration, as to whether or not it would now be included as core patient data. As it stands right now, until October of next year, EHI for information blocking is limited to the data elements in USCDI. I am not going to speculate as to whether or not USCDI will ever exceed EHI by that definition. I cannot speculate on that right now. The only thing I will say, is that we have been focusing on USCDI being core patient data and that is likely the future direction.

Steve Eichner
This is Steve Eichner. I would like to add that one of the things Texas is doing, in addition to this work on the USCDI, is we are also working with the Texas Health Services Authority, which is one of the ONC recipients of the STAR HIE awards. Specifically looking at implementing a proof-of-concept project, for a technology called SANER, which focuses on using FHIR for the exchange of situational awareness data. Some of that data might be derived or included in an electronic health record system at the provider level, but there may be other information that is not contained in the EHR. One of the things we might want to consider to be clear, is working with ASPER and others to establish a second USCDI if you will, that is focused on non-clinical, non-individual information supporting situational awareness data.

I think we need to be careful about not including it or addressing it appropriately, so that the EHR vendors are not including data that is not in their system or does not make logical sense to be in their system. Like the number of beds available, staffing levels, or information that may not be practical to get ported in an HER for subsequent reporting. I am not sure public health is necessarily concerned about what system that the hospital data is coming out of. We do want to be less burdensome on providers to report the data, and whatever makes it easiest for them is important, but we do care about what data we do receive in terms of meeting our data definitions in a timely requirement. I think it is a three-level question. 1.) What do we need? 2.) Where is the best place to store it? 3.) What is the best method of transporting it and exchanging it with public health? Thank you.

Steven Lane
Thanks so much Steve. Let us go to public comment, and then we will come back to you Hans.

Public Comment (01:24:45)

Mike Berry
Operator, can you please open up the line for public comments?

Operator
Yes. If you would like to make a comment, please press star one on your telephone keypad. A conformation tone will indicate your line is in the queue. You may press star two if you would like to remove your comment. For participants using speaker equipment, it may be necessary to pick up the headset before pressing the Star keys. One moment while we poll for comments.

Mike Berry
While we are waiting, I want to remind everybody we will reconvene our task force next Tuesday, June 29th at our regular time at 10:30 a.m. Eastern time. Operator, do we have any public comments?

Operator
There are no comments at this time.

**Mike Berry**
Great. Thank you.

**Steven Lane**
Thank you so much. Hans, were you going to complete a thought there?

**Hans Buitendijk**
Yes sir. Thank you. I want to react to a comment that you made Steven and Steve. From a USCDI perspective, just to clarify, we are not making an assumption that USCDI is limited to EI. That has been part of the conversation from different perspectives. To clarify, we have indicated before that believe that USCDI needs to be able to go beyond EI, because this [inaudible] [01:26:04] is important and critical to interoperability. I was trying to understand where EI fits in. Just to clarify, there is no assumption that USCDI needs to be limited to EI. But understand feedback from my [inaudible] [01:26:21] so far, is that the focus is certainly initially within EI. I think it was a great example that demonstrates that we need not look just at EI [inaudible] [01:26:33].

**Steven Lane**
Great. I wanted to ask Carolyn and Janet to bring us back and orient us to the next steps of their task force, and how this discussion today might impact their recommendations, so that we can understand what is left for our task force to do in our subsequent recommendations. Carolyn? Janet? Either one of you want to comment?

**Carolyn Petersen**
The game plan for the remaining three meetings of the Public Health Data System Task Force, would be to continue reviewing draft recommendations and discussing them this Thursday, as well as responses to the homework that we have sent out. And then we will look to try to finalize those draft recommendations at the July 1 and July 8 meetings. Then ONC will take our output from the 8th and turn that into documents that are sent out to the HITAC for review, prior to the discussion and whatever vote we have at the HITAC meeting on the 14th. I think that what we have today, is very valuable information in terms of better understanding the many complicated issues. In particular of value for individuals who are on both of the taskforces and will be driving those recommendations that come from the Public Health Data Systems Task Force. I think that would be Sheryl, and you Steven, Steve Eichner, and a couple of other people as well. What are your thoughts, Janet?

**TF Schedule/Next Meeting (01:28:47)**

**Steven Lane**
That is great. Thank you so much Carolyn. We appreciate that. We do have three meetings on the calendar for this group. We are meeting next week. My hope is that we will spend that time reviewing in detail, the task three recommendations that our task force has put together. Some task force members have been capturing recommendations that have come out of our last couple of discussions. Those will be on there, but I think we will go back and review what had been submitted previously. We invite everyone to go and review the editable Google doc and add comments to that. We will take off the first half of July. We keep promising you a little time off, you finally get it in the first half of July. We will come back on July 20th. Al
and/or others from CDC will do a deep dive into what will then be the published version 2 of the USCDI and give us a sense of the version 3 submission cycle, and how that has been set up.

Then on the 27th, we are going to be meeting with the folks from the Gravity Project and others to focus in on social determinants of health. I apologize for going a minute over. Thank you everyone for your time and attention today. We will see you next week before a nice break in the beginning of July.

Unknown Speaker
Thanks very much. Bye.

Unknown Speaker
Thank you.

Unknown Speaker
Thank you, everyone. Goodbye.

Adjourn (01:30:34)