HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC) PUBLIC HEALTH DATA SYSTEMS TASK FORCE 2021 MEETING

May 20, 2021, 10:30 a.m. – 12:00 p.m. ET

VIRTUAL

Speakers

Name	Organization	Role
Janet Hamilton	**Council of State and Territorial Epidemiologists (CSTE)**	**Co-Chair**
Carolyn Petersen	**Individual**	**Co-Chair**
Danielle Brooks	Amerihealth Caritas	Member
Denise Chrysler	Network for Public Health Law	Member
Jim Daniel	Amazon Web Services	Member
Steven Eichner	Texas Department of State Health Services	Member
Ngozi Ezike	Illinois Department of Public Health	Member
Claudia Grossmann	Patient Centered Outcomes Research Institute (PCORI)	Member
Steve Hinrichs	Individual	Member
Jim Jirjis	HCA Healthcare	Member
John Kansky	Indiana Health Information Exchange	Member
Bryant Thomas Karras	Washington State Department of Health	Member
Steven Lane	Sutter Health	Member
Nell Lapres	Epic	Member
Leslie Lenert	Medical University of South Carolina	Member
Denise Love	Individual	Member
Arien Malec	Change Healthcare	Member
Clem McDonald	National Library of Medicine	Member
Aaron Miri	The University of Texas at Austin, Dell Medical School and UT Health Austin	Member
Larry Mole	VA	Member
Abby Sears	OCHIN	Member
Sheryl Turney	Anthem, Inc.	Member
Michael Berry	Office of the National Coordinator for Health Information Technology	Designated Federal Officer
Cassandra Hadley	Office of the National Coordinator for Health Information Technology	ONC Staff

Brett Andriesen	Office of the National Coordinator for Health Information Technology	Staff Co-Lead
Brenda Akinnagbe	Office of the National Coordinator for Health Information Technology	Staff Co-Lead

Call to Order/Roll Call (00:00:00)

Operator
All lines are now bridged.

Michael Berry
Great. Thank you very much. And good morning, everybody. And welcome back to the Public Health Data Systems Task Force. I'm Mike Berry. I'm with ONC. And we really appreciate you being with us today. I'm going to open up today's meeting with roll call of the task force members. So, when I call your name, please indicate your presence. And I'm going to start with our co-chairs. Carolyn Petersen.

Carolyn Petersen
Good morning.

Michael Berry
Janet Hamilton.

Janet Hamilton
Good morning.

Michael Berry
Danielle Brooks.

Danielle Brooks
Good morning.

Michael Berry
Denise Chrysler.

Denise Chrysler
Good morning. I'm here.

Michael Berry
Jim Daniel. Steve Eichner.

Steve Eichner

Good morning.

Michael Berry
Ngozi Ezike. Claudia Grossmann. Steve Hinrichs. Jim Jirjis. John Kansky.

John Kansky
I'm here.

Michael Berry
Bryant Karras.

Bryant Karras
Present.

Michael Berry
Steven Lane. Nell Lapres.

Nell Lapres
I'm here. Good morning.

Michael Berry
Les Lenert.

Les Lenert
Good morning.

Michael Berry
Denise Love. Arien Malec.

Arien Malec
Good morning.

Michael Berry
Clem McDonald. Aaron Miri. Larry Mole.

Larry Mole
Good morning.

Michael Berry
Abby Sears.

Abby Sears
Good morning.

Michael Berry

And Sheryl Turney. I know we have some task force members joining us via audio. So, I will capture your names in our attendance. And I appreciate everybody's attention. And I'd now like to turn it over to Carolyn and Janet to kick us off with their opening remarks.

Opening Remarks/Public Health Hearing Recap (00:02:02)

Carolyn Petersen

Good morning, everyone. It's great to see everyone back in the group getting together after our initial meeting two weeks ago. We had an excellent public health hearing related to some of the needs and concerns related to health data systems around public health and interoperability with healthcare last Thursday at the full HITAC meeting. This morning, we will be recapping some of those comments and then, launching into a discussion about surveillance and some other issues related to those technologies and needs. We'll then get into the next steps and have a public comment period. Also, perhaps bringing up some of the homework and additional activities we foresee over the next few weeks as we go through our work plan and see how to wrap this up and present our recommendations to the full HITAC on July 14. Can I have the next slide please? And go ahead, please. And just to get us started and grounded for today's work, I'll review our charge.

This task force is to inform HHS's response to President Biden's executive order on ensuring a data driven response to COVID-19 and future high consequence public health threats. We have two particular parts to this charge. First, we will identify and prioritize policy and technical gaps that are associated with the effectiveness, interoperability, and connectivity of information systems relevant to public health. This would include a focus on surveillance systems, infrastructure improvements, health equity, clinical engagement, research, and innovation, and educating and empowering individuals. The second piece of that is that we will identify characteristics of an optimal future state for information systems relevant to public health and their use. Next slide, please. And at this point, Janet and I wanted to share a few of the high points that we captured from last week's public health data systems hearing at the full HITAC meeting. It was a daylong meeting.

And we can post in the public chat the URL where all of those presentations and the audio are published now. A transcript will be added in the next few days. But we just want to recap a few of the high points for us to get us started. From my perspective, one thing that really came through loud and clear is that we need to build a system that manages every day needs, as well as pandemic related needs. Of course, COVID-19 has figured very largely in the discussion because we're living that every day. But the panelist who spoke to us last week described a broad range of challenges that really go far beyond pandemics and other large potentially catastrophic events. We need to keep the whole picture in mind as we work through the details. And then, second, we also need to do a lot better and to do more in terms of transparency with the public about what is being done, why it's being done, and how this may affect individuals in terms of the movement of their information, confidentiality, and the relationships with the public health system, as well as with their personal care providers.

Health equity is a critical consideration in our discussions and the recommendations that we create and ensuring that it is address appropriately rests, in part, on clear communication and transparency with the public over time. That's really important because it will take time for trust to develop and we need to put ourselves in a position for that to happen to support health equity. With that, I'll pass the mic to Janet for her comments.

Janet Hamilton

Great. Thanks, Carolyn. And I will just welcome everyone also. And in terms of reflections, we did have a number of folks from the HITAC, of course, that were part of that discussion and are a part of this work group. So, I would encourage during this time as well for you all to offer any additional reflection. It was a really robust, all day meeting. And there is just really no way for us to be able to compress all of that information here. And so, I do really encourage members of this work group to take the opportunity to listen or to review the materials. And in addition to Carolyn's reflections, which I would just really like to emphasize that we need an infrastructure that works all of the time. And that is the only way we will ever be able to scale up and ensure that we are also ready during a pandemic response but also to really think about those key health equity issues and that we are keeping that lens at the forefront. A couple of other reflections.

What I'll add to that is I think we heard loud and clear that there is a strong need to modernize. I think we've been talking about this for a long time. And there was broad support and buy in that we have to change the way we do business. My second strong reflection is that healthcare and public health need to be able to share data more efficiently. We have two very important but different functions but the ability for data to move between healthcare and public health is really what's leading to a lot of our limitations. I think the third reflection is that within our own public health system, we really don't have the granularity of information that we need to be able to appropriately track the public health actions and the results of those actions, I should say, the outcome, the control measures implemented, as well as the level of granularity that allows us to communicate effectively to the public in ways where they can really see themselves in the data. My fourth high level reflection is that there is also a huge need to improve, not just the connections between healthcare and public health but really the timeliness and completeness of the data when it arrives.

Public health is often not getting the data fast enough during a response. And then, there is key information that is missing or incomplete, which impedes the public health response. The fifth thing that I wanted to reflect on is that resource management is a huge part of the response. And that is not currently well integrated. And while we do surveillance every day, during response and nonresponse times, the management of resources in terms of distribution of medications or PPE is really not something that public health is doing on a day to day basis. And this resource management piece, availability of tests, etc., is an additional activity for us to really think about how it does impact the public health response and how we can better prepare for that activity when we are needed to do so. I think the final reflection and also to think about our charge and maybe really relates to that fifth component is that given the timeframe that we have, we have a lot to do in a very short amount of time. And there are very likely going to be things that come up during our discussion that are critical.

But we will need to determine as a group if those are really in scope or out of scope given the timeline that we have and the long list of things that we need to do. And I'll just put on the table that one of the things for this group to consider would really be some type of recommendation that there be a standing public health group to be able to continue to address the needs. While we are having this hearing now about addressing the needs of this pandemic and future pandemics, I think we can also all appreciate that while great progress has been made, this pandemic is not over. And the need for continuing to have a body to address issues and be proactive throughout the course of this response will be needed. So, I'll just put that on the table and we can have some discussions about that over the course of our work. So, those were my

reflections. And with that, I really thought maybe there would be some other folks who participated in the hearing that are part of the work group that would like to also offer some reflections.

And I will just say that Arien did an incredible job of chairing that all day meeting. So, let's see. It looks like Arien has raised his hand. And I'm not sure I know how to call on folks appropriately.

Arien Malec
I have the control of unraising. So, first of all, Aaron did a fantastic job. I just sat and listened and made some comments. So, some other takeaways. And thank both of you for those really masterful summaries. Some other takeaways. One is something that I've heard over and over again from states that I did not realize the significance of and the profundity of, which is the degree to which our funding mechanism nationally, actually, impede holistic public health response by stove piping the sources of funding by disease state. One would imagine for contact tracing, we'd be able to use the same infrastructure that we used on daily basis for STD's for emergent needs like E-coli outbreaks and then, be able to scale that infrastructure up for pandemic response. And it seems quite to the contrary that we don't build our infrastructure from that standpoint. And that gets me to the second observation, which is that public health is a system. And we have not taken a systems response or a network response.

One of my favorite examples is that the ISP task force, public standards priority task force, did a deep dive on the orders and results of infrastructure in this country. We haven't standardized the orders and results infrastructure for this country. We did that from the basis of improving clinical workflow that if I can standardize ordering and resulting, I get bilateral information flows. But as it turns out, in the public health response, we were missing critical information such as address, contact information, and demographic information on lab orders that would flow through to public health. So, it's a plea to think about incenting the system, making sure that when we incent as we did early on provider organizations for meaningful use that we're also thoughtful about funding public health to make sure that we have the same standards in interoperability on state systems. And to the extent that we look at information flows to improve clinical workflow that we're also mindful of how those information flows improve our public health response.

So, again, just underlining this notion of thinking about incentives, thinking about funding sources in concert and thinking about certification requirements and mandates in concert to make sure that we're not inadvertently funding one part of the infrastructure but not funding or incenting or mandating the information flows that are necessary to get the end to end response done. And then, the third observation is the extent to which, potentially in a future public health information system, we do what, I think, many people have called for, which is that public health is healthcare. That social determinants of health and chronic disease management is on a continuum with public health. I think if you look at the early work by public health professionals in New York City thinking about smoking cessation as a public health activity or thinking about an obesogenic environment as a public health activity, we should start to think about information systems that start to harmonize healthcare and public health as a continuum as opposed to healthcare is over here and public health is over there.

So, those were my three big takeaways really just doubling down on this notion of thinking about our public health infrastructure as a system but it's continuous with healthcare delivery and public health response. Thank you.

Janet Hamilton

Those are fantastic. I wholeheartedly agree with those really important reflections. And in particular, I think the comments about public health is healthcare and how this is an opportunity for us to really look in different ways about how we have done this and how our system can and should work. And I agree with your other comments as well, in particular, the funding pieces, too. It looks like we have a couple of other comments. So, let's turn to Bryant.

Bryant Karras

Thanks, Janet. And apologies. I still need another cup of coffee before I'm completely coherent. I was able to listen in to the entire testimony. It was amazing to hear so many people compress their thoughts into five minute intervals. And I only wish that we were able to go into a deeper dive with a couple of the presenters. One of the things that I think is important that we as a task force don't miss is that if we stay at that surface level, we may inadvertently miss key differences in approaches. I think if we peel back under the hood, a couple of different presenters who presented things that on the surface seemed consistent, the approaches that the respective states had take were, actually, fundamentally different architectures and may be difficult to reproduce state by state. So, I think that there are potential challenges that we may run into if we don't go that next level deeper to truly understand the implications. So, I think that's something that's important for us to keep in mind and take into consideration as we progress this activity.

And then, three other points, if I may but quicker. Resources and planning and coordination and evaluation. I think one of the things that we've lacked in our public health systems approach is due to that siloed funding, there not being overarching coordination between different program areas or organizational participation in important national activities, such as standards bodies, HL7 organization, committee membership time protected in CSTE work groups, etc., that a minority of states and local health jurisdictions have been participating in those activities. And it's reflecting in the adoption of those standards and of those efforts state by state. So, we really need to try to figure out how, when we do this modernization, we do it, not just as a one off but as a sustainable modernization where we have participation in these ongoing modernizations and ongoing keeping current our participation in the healthcare sector. That was longer winded than I intended.

Training and workforce development, critical. And I'm just continuously reminded of the Japanese proverb, "The best time to plant a tree is 10 years ago." And that's really what we're up against now. We need this workforce to have 10 years of experience. But we might as well start now so that 10 years from now, we'll have the workforce we really need. And I can't agree more with the funding challenges and requirements. That shared infrastructure, we ended up in Washington State, just to make a concrete example. We put in pieces of funding for shared infrastructure across different siloes because there was, actually, allowance for up to 10% of a particular grant or CDC block to be used for shared resources. But in the year by year funding cuts that occurred, of course, those shared resources were the first things to be cut. So, we really need to make sure that that kind of investment is emphasized as not an option but as a requirement to making things work. Thank you.

Janet Hamilton

Great. Thanks. We have two more comments. I will ask that folks who are going to make comments, so John and Clem, that we try to bring out things that haven't been brought out yet just in the interest of time. So, John.

John Kansky
Thanks. I can be brief. So, I was very impressed with the diversity of perspectives I'm hearing. And it was incredibly helpful to me to kind of prime me for the task force with the richness of the perspectives. One thing that I did hear that I'm sure we're going to get into as a task force that's going to be vexing is I think there is general agreement that we need a future public health information system that works every day and during emergencies. But I heard some advocates for a public option. I inferred that to mean a government run option. Some people but not everyone linked that to the potential for the future TEFCA. I heard some advocating for using existing interoperability ecosystems such as they are, HIE's, EHR's, some of the national frameworks and networks. And then, I heard others advocating for leaning heavily on the future API capabilities of EHR's nationwide beginning in 2022. So, those are not necessarily compatible vies of how we do this. So, I'm looking forward to the discussion. Thank you.

Janet Hamilton
Great. Thanks, John. Clem.

Clem McDonald
Yeah. I wanted to bring up that I just got off a call with the LOINC committee with a lot of lab people. And the issues about not getting patient registration information, address, etc., are very deep and complicated. So, the railroad that now works pretty well in terms of delivering is the ALR system, which sends laboratory results from laboratories to public health. And the challenge is an awful lot of those laboratories never get registration information. They get just an accession number for the specimen. And that's a historical reality. And it may relate both to the fact it's simple or easier and perhaps even less constrained by HIPAA. I don't know if that's true. And the other mechanism is the ECR, which is the case report, which is new and is very, very limited. The infrastructure isn't built out very well yet. That is not happening very well. So, we have to face up to that and either figure out a way to get the registration data sent along the ALR and all the issues that would be related to that or they'll push ECR harder.

And ECR in some systems is not painful to users because the medical record system pulls the stuff together and sends it up. I just want to pay attention that we get down in the weeds when we hear about all of these problems and not just stay at 30,000 feet.

Janet Hamilton
Thank you so much, Clem. And I think that order process as we think about labs is a critical piece. And I hope we can have a future discussion in one of these calls that really delves into lab issues. It is so critical and even some on this call. I see we have two other folks that have raised their hand. But I think in the interest of time, I'm going to go ahead and pass it back to Carolyn and, Les and Larry, hopefully, we can get your comments also worked in as we move through some of the discussion questions. Carolyn.

Review Surveillance Discussion Guiding Questions (00:27:40)

Carolyn Petersen
Great. Thanks, Janet. And thanks, everyone, for those insightful reflections. Whenever there is a long hearing like we had last Thursday, there's a point where there's so much information that it starts to roll around in your head. So, I really appreciate people bringing forward some particular issues that really stood out and maybe strong considerations as we start putting together these recommendations. We're now going

to start into the discussion around surveillance. This is a discussion that we will hold today and at next week's meeting. Ideally, we will be able to manage it in that timeframe. I will start by reading through all of the questions broken out in subsections across the next four slides in the slide deck that you received. And then, we'll roll back to the first page of questions and Janet will start that discussion with me kind of moderating and calling on people to try to keep us moving. So, with that, if we could have the next slide please. This is a question relating to the data standards aspect of surveillance. And I'll read that for the benefit of the individuals who are just on the phone and don't have the text in front of them.

For the key surveillance use cases, what major gaps exist in health standards that prevent data from flowing between clinical and public health entities? And what additional standards might need to be developed, further tested, or harmonized? Here, we want to keep in mind that surveillance use cases include but are not limited to testing, case reporting, syndromic surveillance, and immunization. Next slide, please. So, here are questions related to sharing, use, linking, and integrating data. First, what real and/or perceived barriers exist that continue to inhibit progress in integrating multiple public health, social services, and clinical data sources while responding to public health emergencies? And we're looking at that from a technology and infrastructure perspective, from a policy, licensing, and legal perspective, from a patient privacy, digital access, and social justice standpoint. And then, also the federal versus the state and local. Next slide, please.

Now, we come to the health equity and surveillance systems aspect. Here, we have two considerations. First, how do we ensure that surveillance systems adequately identify potential sources of bias and health inequity and address health equity? And then second, what streamlined data sharing between social services and public health could enhance surveillance efforts and overall emergency response? What, if any, work would be needed to ensure accommodation of individual's desire for and right of access to protected health information? Next slide, please. And finally, a significant consideration, of course, case reporting. Here, the question is how can we reduce the manual public health reporting burdens for providers across the care continuum and support services? What steps and incentives are needed to scale automated methods of case reporting, such as ECR? And we're thinking here from the perspective of large hospitals and provider networks, for long term care and support services, and for community providers.

So, now we will go back to the first slide of questions. That's No. 7 if you have your slide deck open. And look at data standards. And I don't see any hands up yet in the cue. Do you have any comments, Janet, before we start calling on individuals?

Discussion (00:31:56)

Janet Hamilton
Great. Thanks, Carolyn, for reviewing those. And I think Clem was just bringing up some issues around standards and how we make improvements in the entire process. So, I would just love for folks to think and reflect through on this and recognize that we are asking people to really comment on these major use cases that are listed there. So, the testing, case reporting, syndromic and immunizations but also if there are other things that you feel need to be brought up, please do so as well.

Carolyn Petersen
And with that, let's get started with Jim Daniel.

Jim Daniel
Hi, can you hear me okay?

Carolyn Petersen
Yes, we can. Go ahead.

Jim Daniel
So, I'm going to bring up an issue that I hear from the provider side that I think is really important. I don't think we have as many folks from the provider side on this and I'll start with that viewpoint. Onboarding, getting to the point where you can, actually, send data for all of these use cases, electronic lab reporting, immunization, case reporting, syndromic surveillance is really tough. And a lot of the reason that it is so difficult is the variations that still remain among states. I think from the beginning of HITAC and meaningful use thinking 10 years back now, 10 years plus, I think the public health community has done an amazing job getting rid of a lot of that variability and standardizing as much as possible. But there is still 10 to 20% that's left. And it's still causing a lot of issues to make it easy for providers to connect to these systems. I'll just throw out the immunization gateway, for example.

As providers are connecting to immunization information systems through the immunization gateway, they still can't send exactly the same query, exactly the same message through that gateway. They still have to tweak it a little bit for each of the states. And I think it's really important for us as the public health community as we are modernizing these systems to go back and get a little more strict on our implementation guides and have something that works everywhere. I, certainly, understand that there are some variations that are required by state law. And I know Denise can speak to that at great lengths for immunization. But I do think there are ways to write the implementation guide that it's still a single implementation guide that works across the country. That's a really important part, I think, that we shouldn't forget about. There are lots of other things that I think we need to do but I'm just going to throw that one out there to start us off.

Carolyn Petersen
Thanks, Jim. Let's go to Arien Malec.

Arien Malec
Thank you. So, in many cases, what we have is not a failure of standard but a failure of use of standard. So, as Clem noted, in many cases, our commercial labs are getting accession numbers. They're not even able to capture sex or racial based differences in lab results because they don't have the base demographic information to do that. That's, actually, tied to billing requirements. All labs need to do to get billed is get the insurance information and the very, very minimal patient contact information, as well as minimal information on orderables. And as long as they can link that to an insurance card, they're more than happy to do the test and get paid. That's inadequate for the public health use cases that we saw. We have plenty of well-defined standards that are, actually, reasonably well tested. Back in the early days of the work that we did at ONC, we created an LOI and LRI implementation guide for orders and results. We never put the incentives in place for provider organizations to use those guides, nor do we have the incentives in place for labs to use those implementation guides.

And it's a biproduct of not the failure of standards. It's a biproduct of the failure of the incentives and a biproduct of the failure of the incentives that we do have, which are primarily payment based incentives that

led to the example that we have. In other cases, I think for ADT based surveillance or, as Ken Mandl was calling for, more advanced chart based surveillance, we can do a better job of having standard ADT implementation guide. But again, I think the standards that we have in place are probably good enough for ADT based public health surveillance for ILI. What we don't have, again, are the incentive structures and funding mechanisms to ensure that all hospitals, including hospitals serving the underserved, have the funding to be able to implement those guides and the infrastructure on the public health side to get that information.

I do think there is standards development that is need around more advanced cases such as being able to use the chart information or documentation information to be able to pull out a more comprehensive picture. I do think ECR could, actually, be used both as a case reporting standard but also a surveillance standard with appropriate triggering conditions. It could end up being a replacement for the reportable conditions standards that are a little stove piped in the CDC implementation guide. We might want to replace those with a single ECR standard and then, have more flexible trigger conditions that can flow down to EHR's. But, again, I think we need to make sure that we have the incentive structures right to make sure that all health systems and hospitals can implement the ECR standard and make sure that we've got the infrastructure for sending the computable triggers down to those institutions. So, again, just doubling down on this notion that, in a lot of cases, we have plenty of good standards.

We just don't have the systems that encourage standard views. There are cases where there are additional standards adopt necessary. And as I said, I would point to ECR, potentially, as replacing the reportable condition standards as a more flexible infrastructure for being able to do trigger based case reporting. I think what we heard was that public health was often getting the ECR cases when those were wired up faster than they were getting the ELR cases. And, certainly, I don't think we got any of the reportable condition cases in the COVID case because it wasn't a flexible enough standard. So, thank you.

Carolyn Petersen
Okay. Let's go to Clem McDonald.

Clem McDonald
So, I would like to just comment on the way one has lumped all of this stuff under surveillance. I don't think that's helpful. You ought to start breaking them out because I don't see how immunization is exactly the same as surveilling for the **[inaudible] [00:40:23]** occurring. And maybe **[inaudible] [00:40:26]**. But the other thing is regarding the ELR/ECR, the problem with the constate is I don't need to get insurance information by patient. They charge back to the institution and send them the request. So, it's a very deep problem because their systems are often connected up as direct one to one, the institution, the hospital office to a lab and they just stuck in the accession number and off it goes. So, there is a lot of rewiring that would have to be done. I think we need to do it probably but we need to realize this isn't just declaring we want to do it better and it happened.

Carolyn Petersen
Great. Thanks, Clem. Let's go to Larry Mole.

Larry Mole
A mic check first. Do you have me?

Carolyn Petersen
Yes, we have you. Go ahead.

Larry Mole
Thank you. Sorry. We've been having phone problems today. So, I agree with the last comments about parsing out what's on the slide here. But I would like to hit on a few of the things relative to surveillance. And I think one of the things listening to the group here and things we struggle with is the authoritative source for information. And so, when I think about the process that's been laid out about sending the lab, we might do a send out to lab, the data is going to come back to us. And where you would get the demographics, the social determinants would be out of our EHR. So, we may need to think a little different about the kind of data and information that comes direct from a lab service, a PBM sort of thing, is different in terms of the intent of it and what you use it for versus something that comes out of something that's classified as an authoritative source where it's a more complete data set.

A few other things that came to mind through this is I think the public health approach kind of, at least through COVID and some other surveillance related to pandemics, we fall into some traps related to whether we're patient centric or population centric. And, again, that drives what sort of data, what sort of quality and so forth. So, I think there's homework to do about what it is we're trying to do. And then, based on that, I think that will help with the gaps and so forth. A third area I think about with this is related to a bucket of surrogate markers. So, we've done a lot of work through COVID looking at employee leave across the enterprise and using employee leave as a predictor of where we may have a COVID outbreak. We did that early when we didn't have enough COVID testing. So, I think there are alternative data sources that we should think of how they fit in ala ILI work. So, whether it's getting data from CVS and Walgreen's about over the counter drug use, whether it's some of the Google data about looking at top search hits related to what we think is a healthcare thing or some ideas.

And then, core surveillance, I think about the examples of what that looks like Wuhan early on versus what it looks like in Seattle or Northern California when it was on the west coast where that ladder model you had much more information coming in and you even had somewhat of a test early on. But the surveillance model is going to be different clearly. We all know that. But I think let's not forget that. And then, one final thing, I think, from our own side and our own federal agencies is I think we can improve the way that we roll out whether it's an ICD-10 code or a procedure code or whatever is appropriate that helps us identify the population. So, the time it takes and where we're trying to have the right data to be able to do appropriate surveillance on something that's unknown or barely known, it would help if early on we had a flag and could start to understand that particular subset of population. I don't know the best way to do that but I think we did some work because we have our own internal system so we flag people early on before their ICD-10 codes. And it helped us track the population. So, just some thoughts and I'll stop there.

Carolyn Petersen
Thanks. Let's go to Les Lenert. Les, you might be on mute.

Les Lenert
Thank you, yes. I'm here. A couple of points about the standards development, which was the focus of this. Emerging standards like FHIR offer new opportunities for public health to integrate with the healthcare

system by changing the directionality and the ability to capture data on cases that evolve over time. The thought here is that once there's a trigger like a lab test order that gets to public health that the ability of clinical data systems to respond to FHIR queries from public health allows them to complete missing information on demographics, age, other types of issues for testing cases. It is important for public health to get notification of testing to get both the numerator and the denominator. Similarly, for case reporting, a one-time case report triggered from an EHR is not as useful as being able to offer public health access to capture additional data and keep its records up to date as the case evolves inside the clinical care system and that this is only really possible with the FHIR standard based approach where public health can query the clinical care system.

Syndromic surveillance is an important evolving area. We refer to that either as ADT surveillance or perhaps it looks at surveillance that occurs before ICD-10 codes exist for the patient or before they're really generated. Here, we need to think about standards that allow the transmission of textual information directly to public health to conduct a kind of surveillance that is necessary. With immunization registries, again, the ability of these immunization registries to respond to queries in standards based way from the clinical care system is critical. Here, expansion of their capabilities to include bulk FHIR would be important to allow health systems or healthcare providers to access data on their patients a population at a time to prioritize care and to be able to direct outreach efforts to the patients who need it the most. Currently, immunization systems have a standard for response. But it's focused on one patient at a time access, which is not really adequate for the population level activities that are going on with the health system to get vaccinations out to a group of the most vulnerable with limited resources.

Carolyn Petersen
Thanks, Les. Let's go to Jim Jirjis.

Jim Jirjis
Thank you. And I just want to, first of all, echo towards the comments of the group about FHIR, about incentives and everything. Also, as a provider, I wanted to outline some of the challenges we have that we observed being in 20 different states and having to interact with 20 different states' Public Health Departments and just emphasize the whole point to point thing has just got to go away. And it's sort of a many to many problem. So, whatever solution should really simplify that because the amount of hours and effort spent contracting, testing interfaces, and dealing with the variation that comes from the lack of implementation guide existence and adherence created an enormous distraction. And more importantly, it create delay in the space in the federal government getting the data they needed to manage the pandemic. So, the first point is moving away from the point to point. The second point is a real endorsement of implementation guides.

We had, for example, one Public Health Department at one field was missing the entire file, was rejected, and it had to be scrubbed and fixed and resubmitted. Other states accepted the blank field. And a bunch of different efforts around interpretation. The other two comments I wanted to make were around incentive. So, there was a bit of incentive with meaningful use but it was a little meager. And it was only directed at the providers to satisfy penalties to be able to show you were in good faith working towards an interface with public health. And eight years later, five states that we interact with had not ever gotten around to it because of funding, etc. And how do you incentivize the lab systems, the Public Health Departments, and providers so that once you do have standards and implementation guides, people, actually, adopt them?

Those are the observations that we painfully felt during the pandemic and that we hope are part of and are addressed to make this solution, actually, workable.

Carolyn Petersen
Thanks, Jim. Let's go to Danielle Brooks.

Danielle Brooks
Good morning. I agree with several of the comments that the other speakers had raised. One comment I do want to make is that, as we explore these standards, there are timeliness standards that really impact, particularly, the payer standpoint. One of the difficulties that we experience from the NCO perspective is just the timeliness of receiving data and accurate data from our state Health Department, which had an impact on being able to understand the scope of the impact, who was impacted, and where that geographical access was. So, because each state is inconsistent in their turnaround time of data and completeness of data, there really was that inconsistency in terms of outreach and understanding the level of impact. So, as we consider this, I think it's also important to keep that payer perspective, particularly, the folks that are participating in Medicare and Medicaid and long term services because that type of standardization allows for a better, consistent outreach and support other structures like the providers, community based organizations, and outreach to potential patients and **[inaudible] [00:52:40]**. Thank you.

Carolyn Petersen
Thanks, Danielle. Let's go to Bryant.

Bryant Karras
Thanks. I'd like to focus in on standards for a minute and make sure that we don't get lost in time and be stuck with the standards we have currently. So, one thing I'd like to remind is we wouldn't have syndromic surveillance if we had stuck to the standards that existed in 2000 and just adhered to rigorous compliance with the status quo. And if not for a few states that pushed out ahead of things and created a new, innovative approach, coordinated with each other to come up with a common standard across the program and then, ultimately, CDC joining in to the approach and saying, "Yeah, that is a good idea. Let's add that into our toolkit." I think that's going to happen again. And we're seeing it happen again with new innovations and Bluetooth exposure notification, for example. But what we need to do is make sure that we are adhering and creating common implementation guides but leaving space for innovation and investing in proving out and keeping things working forward.

One additional example, I'll say, is the race and ethnicity data and sexual orientation and gender identity. We've got really bad data because we haven't made improvements to that standard in more than a decade. And my own state is trying to push the envelope and has pushed it beyond what's technically implementable, which is posing a challenge for us here. So, I think we really need to put some investment into resources that can help make these improvements. I'll leave it at that. I think that maybe one of the recommendations this task force can make is to invest in national organizations that can really help to evolve and maintain these standards. Thank you.

Carolyn Petersen
Thanks, Bryant. Let's go to Steve Eichner.

Steve Eichner

Thank you so much. Just a couple of points kind of building a little bit on what Bryant was just speaking to is looking at harmonizing standards across the different data collection efforts that we're making. We've made efforts to do that previously. I think we need to keep that as an ongoing activity. I think we also need to consider what public health can return to the provider community in terms of new data or analytic services so that there value shared participation in the value of the data exchange and that it's not just perceived as a Band Aid to report data because they're required to report data. But there is, actually, an information return for supplying that data. At the same time, I think we need to consider who has got a stake in the particular kinds of data. Laboratories, for example, may not have a business interest in some of the **[inaudible] [00:57:10]** questions that public health is interested in and healthcare providers serving the patient in regular services may be interested in.

So, how do we adapt our standards to support that, potentially, leveraging HIE's or data previously collected about a patient that doesn't necessarily need to be recollected because it doesn't change? And that would help us reduce the modifications to systems to collect and store what is relatively unnecessary data to that particular provider. The laboratory, for example, may not be terribly interested that I went to Aruba last month as part of a travel history. But public health may be very much interested in it. Why have the laboratory modify its system just to receive and forward that data? Are there other ways to look at providing that data to public health? How do we best leverage this? So, I think there is a lot of opportunity. We just need to figure out how to make it work. Thank you.

Carolyn Petersen

Great. Thanks. Now, I'll ask if there are any task force members on the phone whose hands I can't see, could you announce yourselves please. Okay. Let's go to Denise.

Denise Chrysler

This is Denise. I guess I'm confused about how one gets recognized. I just have a question.

Carolyn Petersen

Go ahead, Denise. I'm working on the site but also calling on people who are just on the phone. But please, go ahead.

Denise Chrysler

Oh, okay. I just had a question. My assumption has always been, and I agree with all of the comments about laboratories don't need particular information. Should we expect their systems to collect it to pass it onto public health? I had always been under the assumption that there is some sort of linkage by public health of case reports and laboratory reports because the same kind of conditions have to be reported that arise out of the electronic health records. The problem would be that the case reports may not as quickly make it to public health or as reliably make it to Public Health Departments as laboratory reports do. And so, that was the question I wanted to pose for those who know more than I do.

Janet Hamilton

This is Janet. And I'll respond to that and just in the interest of time, we probably need to go onto the next question. Certainly, public health does a lot of matching on the backside. What I would say is when there is a lot of missing information that comes in, it also makes that matching process a lot harder. And in today's

world, unfortunately, because of some of the challenges in terms of receiving case reports at all, many times the lab result is often the only thing that's received to start the process. And then, public health spends a long time trying to fill in the pieces. And I think that's where we have some opportunities to maybe rethink things. But great comment. So, anyway, I'm just going to go ahead and move us on. So, Carolyn, do you want to go ahead?

Carolyn Petersen
Sure. I did want to say I see one more hand up. Steven, is that Steven Hinrichs? Okay. Let's go forward to the next question. We seem to be having some challenge here. We can circle back if we need to. So, now we're back at the question related to sharing use linking and integrating data. And the question here is what real and/or perceived barriers exist that continue to inhibit progress in integrating multiple public health, social services, and clinical data sources while responding to public health emergencies. This is the technology and infrastructure perspective, policy, licensing, and legal perspective, patient privacy, digital access, and social justice perspective. And then, of course, federal versus state and local. And I see Jim Jirjis has his hand up so let's start there.

Jim Jirjis
Thank you. On the data and data sharing, one of the things that happened in the public health emergency was the need to create data standards, for example, for the laboratory companies to adhere to and be nimble and quick about creating them and enforcing them. Well, we, for example, as a single hospital might experience reagent shortage and might to on a dime flip to different testing laboratories or methodologies. And Problem No. 1 was there was an incredible amount of effort trying to map all of those different mnemonics, not only the lab result but what lab they came from, etc., consumed an enormous amount of time and burden. And then, the second course was the actual sharing of the info. In the middle of the crisis as a hospital, we would see a patient who might be tested at the Public Health Department. And they're communicating rapidly that response was a telephone call to our infection prevention nurse who then would go into a spreadsheet and type in the results so she could do her job.

When we had to report positives that were admitted, anything we had done testing on or anything that we hired a lab to do testing on, we got that automatically. We had to do some value set work to report on it. But when patients came from other hospitals tested elsewhere or tested in public health, we had the compounded problem of not having a good way to have the information be shared. And we had to, actually, create we called them the COVID information tsars. And their full time job was to look at every admission and try to figure out how to get that COVID test result PUI versus result information into our data systems so we could apply the value sets in the report. I wanted to give some color to those challenges as we address this.

Carolyn Petersen
Thanks, Jim. Let's go to Denise Love. You might be muted, Denise. Denise, are you there? We're not able to hear you.

Steve Eichner
Was that Steve Eichner or another Steve?

Carolyn Petersen

Let's go to Bryant Karras while we work out the technical issues with our speakers.

Bryant Karras
Thanks. Who was the last speaker?

Carolyn Petersen
That was Jim Jirjis.

Bryant Karras
So, granted we were hit by the pandemic before any other state but way early in the process, public health was for a period of time our state lab was the only lab outside of CDC that was doing testing. We quickly pivoted to and worked with the Attorney General to make sure that we had the ability to do this to send outbound COVID test results reversing the flow of notifiable conditions and sending them out through the health information exchange so that every Emergency Department in the state had laboratory test results available to them at the time the person was checked in by the clerk at the front desk and so that the appropriate conditions can be put into place. It was really surprising the resistance that we got to that initially because it was something that public health hadn't done before. We had always been the recipient of these lab results. So, it really kind of turned things on its head. And I hope I'm not breaking any rules here calling out the differences.

But I'd love Denise's help. When we tried to repeat that same process to our southern border because some Washington State folks would be showing up in Portland based hospitals, Oregon had laws on the books that prevented that same process from going into place. And it was really a bit frustrating. I think that variation is going to be very challenging.

Janet Hamilton
This is Janet. And I might just react to that before we go onto the next question, Carolyn. And that is we saw that issue during H1N1, too. And in many situations where the public health labs served to do enhanced testing, the result returning piece becomes a huge issue. And I think it is something for us to explore. We saw it during Zika as well. Because of the broad testing for COVID, I think that pressure point quickly changed. But one could imagine in a future model that that could be a huge issue. I'm sorry, Carolyn. Go ahead.

Carolyn Petersen
No, that's fine, Janet. I just wanted to let the task force know that we think we've ironed out the audio issues. And I will recognize you before speaking to try to keep the conversation on track and avoid cutting each other off. Denise is on the line now. So, let's go back to Denise Love for her comments.

Denise Love
Yes. And I'm sorry that I missed out on some of this conversation trying to get connectivity. Can you her me now?

Carolyn Petersen
Yes, we can hear you, Denise.

Denise Love

And this may not be relevant to the conversation that just preceded, but the sharing and linkage and integration of data, in general, is hindered by the lack of identifiers and patient identity and also the fact that it takes weeks or months to work out data use agreements or data sharing exchanges. And it gets even more complicated across border. So, I talked with a major state yesterday on a linkage project and it's taken months to get the agencies aligned so that they data could be properly linked and analyzed. Thank you.

Carolyn Petersen

Thanks, Denise. Let's go to John Kansky.

John Kansky

Thanks. Hopefully, amplifying and to being redundant with some of these state level policy barriers that Bryant brought up and others are commenting on, I think there are many, many examples that are relatively easy to fix within each state. I'm not commenting on the problems of different policies across states. While that is a problem, I'm just saying that there are barriers within each state that I believe are unintended consequences. I'll give just a couple of quick examples. Immunization registry roles that very narrowly only allow the Public Health Department to share data with providers only, covered entity providers, one at a time. That sounds right when you're setting up an immunization registry. But in a pandemic when you're trying to, for example, leverage your health information exchange as a way to get that information out, it's a problem.

And then, the second quick example, which was even, to me, more unexpected or harder to anticipate, not unexpected, was the Public Health Department wanted to rely on HIE in different states as a means to get an aggregated single source of data. And hospitals were not allowed to share data or perceived that they were not allowed to share data with the health information exchange and required governors' orders to sort of declare the HIE to be agent of public health. And that shouldn't be necessary. Thank you.

Carolyn Petersen

Thanks, John. Let's go to Jim Jirjis.

Jim Jirjis

Yeah. I wanted to make one more comment. I know I've made several. My apologies. One was that whatever the solution, the other thing that we encountered that became kind of a burden that I think is relevant here is there was sort of a federally defined requirement some of which could go directly to tele tracking or work through your state. And then, there were things that had to go through your Public Health Department. But one of the things we identified is there was such variation in states. One of our states added an additional 60 plus questions. And they were completely different. They weren't just modifications with different data definitions of the federal set. And so, there was a plethora of additional reporting that had to occur. And often, requirements were posted by the state or federal level that were business requirements without really true data definitions and then, a short time to execute.

So, my comments are whatever solution has to also embrace the breadth and variety of additional data elements that the states come up with in addition to making sure, whether state or federal, there is enough diligence and specificity to convert business requirements into actual informatics data definitions for people to be successful in sharing this data.

Carolyn Petersen
Thanks, Jim. We are approaching the time when we need to do public comment. So, I will ask for comments from Nell and Sheryl and then, we will go to public comment and then, wrap up. So, Nell Lapres, please go ahead.

Nell Lapres
Thanks. I'll keep this quick. I think just to echo what Jim said, I think that there really needs to be clear expectations about who is, actually, responsible in government for soliciting and collecting data from stakeholders and that there is very clear data definitions of what the metrics, actually, mean that account for nuance that occurs within healthcare organizations. So, I think having that be more clear or us defining more clearly what the metrics should look like going forward is going to be really important for future events like this. I also wanted to just echo, again, that the patient matching that I think Denise brought up is difficult to, not just within reporting for healthcare organizations to public health but also there is data that healthcare providers share with one public health agency that could supplement data from another public health agency much like the silos that we were talking about a little bit earlier on this call.

And having consistent patient matching logic and patient identifiers, I think, will allow for a breakdown of those silos both within a state but then, also across jurisdictions and really help keep consistent patient history and allow us to best care and understand the patients' history, which I think is important.

Carolyn Petersen
Thanks, Nell. And let's go to Sheryl Turney.

Sheryl Turney
Thank you, Carolyn. I did want to bring up that based on our experience, the current immunization registries are really set up for data submitters and not for data use and sharing. So, when you go through the process to try to access data, there is, in many cases, the self service model. But it really only applies to submission. The legal agreements similarly are only applying to submission, which is why, as Denise mentioned, it takes so long to get an agreement in place for using data in some other way. And so, guidance needs to be provided along those lines. And then, I believe someone else brought up the issue of the local legal requirements or rules in each state are also different. So, in some cases, being able to provide an attribution list for patients and be able to get that data back is problematic because of the way in which the data is kept. It's not able to match up on patient identifiers. So, trying to level that across the ecosystem so that there is consistency for data use as well as data submission, I think, is really, really important.

Carolyn Petersen
Thanks, Sheryl. Before we head to public comment, did you have any recap thoughts, Janet, or any responses to this discussion so far?

Janet Hamilton
I would just say I think it's been a really robust discussion and conversation. And I think we have a few things for us to think about as a group, too, in terms of how we can break this up so that we can start to solidify some of our thoughts around where we have consensus and then, where we need more exploration.

Public Comment (01:16:43)

Michael Berry
All right. This is Mike with ONC. And I think we're ready for public comment. So, operator, if you could please open the line for public comments that would be great.

Operator
Yes. Thank you. If you would like to make a comment, please press Star 1 on your telephone keypad. A confirmation tone will indicate your line is in the cue. You may press Star 2 if you would like to remove your line from the cue. And for participants using speaker equipment, it may be necessary to pick up your handset before pressing the star keys. One moment while we poll for comments.

Michael Berry
And just a quick reminder, we will be back next week to rejoin the task force on Thursday, May 27 at 10:30 Eastern Time. Operator, do we have any comments?

Operator
There are no comments at this time.

Michael Berry
Thank you. Carolyn, Janet?

Carolyn Petersen
I think probably we should wait another minute or so for public comment and circle back. Sometimes, people have a little bit of trouble connecting or getting through with the operator. Did you have any announcements or other clarifications Brett or Brenda?

Next Steps (01:17:56)

Brett Andriesen
Yeah. So, we will be sending out some additional information and homework assignments for the team. We are going to be leveraging and I know a few folks that provide some responses to these questions in advance via a Survey Monkey tool. We will be adding some additional surveillance discussion questions for future topics to that. And we'll be sending those links out very soon. So, take a look at those. Ideally, if we could have folks in advance submit responses by Tuesday morning that will give us some time to compile everything, get the group's responses out to everyone, and make for a smoother discussion with some advanced thought there. And we're also going to look at ways to be adding some additional time in existing meetings or maybe schedule some others just to make sure that we have sufficient time to cover all the topics clearly. We did not get through everything that we were hoping to today. And I just want to make sure that we're able to cover everything we need to for our charge.

Carolyn Petersen
So, let's circle back again on the public comment if we have anything here.

Operator
There are no comments at this time.

Carolyn Petersen

Okay. Thanks. Let's move forward to the next step slide. And I think Janet had some thoughts about what else we will be asking you to do and how we'll be integrating some of the feedback that you're providing. I think it's clear from today's discussion that we really have a lot of good perspective that we can use to build those recommendations. And perhaps our problem may be that we have so much that we struggle a bit to bring that into a coherent, succinct piece. But that's the right problem to have for sure. We want it to be comprehensive in our response in our recommendations to ONC. So, let's take a look at our next steps. We'll ask that you complete those Survey Monkey surveillance discussion questions that we've discussed today. I know that went out not very long ago. If you could wrap those up that would be really helpful. We've already received a few responses but we want to be sure that we get feedback from everyone on the tsk force who is interested in doing that or has something to share. We will be adding some additional surveillance discussion questions as well to Survey Monkey.

That would be tomorrow. The slide says Friday, May 22, but it will, actually, be May 21. And we'll be sending those out to you as well. We request that you submit those responses by Tuesday, May 25, at 10:00 a.m. Eastern. That will help us to be able to synthesize some of that and help to steer the discussion next week and identify anything that we need to discuss further to clarify points or try to get some consensus around it. I know this probably seems like a lot and we are making an ask over a weekend. However, we have a large task and we want to provide the absolute best, most comprehensive recommendations to ONC that we can. So, we appreciate your help and cooperation. And with that, I'll now pass the mic to Janet for additional follow up or discussion.

Janet Hamilton

Thanks, Carolyn. And thank you all for just such a really robust discussion. I think we will definitely be meeting internally based off of this conversation today to think about how we can have a few more focused conversations within this really broad landscape so that we can achieve that progress that I think we're all looking for. And I would just say this is complex and we all knew it was. And that's in part why we're here. And it's also why this conversation is so needed. So, really just thank everyone and I would just say if other folks, in addition to completing any of the survey questions, have thoughts on how they would like to break things apart, of course, we will be talking about that and are happy to take feedback on that as well. So, thank you all very much.

Michael Berry

Okay. Thank you, everybody, for joining us again today. And we will see you next week. We are adjourned.

Adjourn (01:23:18)