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

May 27, 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
All right. Welcome, and thank you for joining the Public Health Data Systems Task Force. I am Mike Berry with ONC, and I would like to thank our co-chairs and the entire task force for their hard work. We really appreciate everyone's participation today. And, just a reminder that we welcome public comments, whether through the public comment period held toward the end of each meeting or through the public chat features, and you are also welcome to submit written comments to onc-hitac@accelsolutionsllc.com. All public comments are included in the meeting minutes and all meeting materials can be found on healthit.gov. So, let's get started with roll call. When I call your name, please indicate your presence, and I will begin 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 am here.

Michael Berry
Jim Daniel?

Jim Daniel
Good morning, I am here.

Michael Berry
Steve Eichner?

Steven Eichner
Good morning.

Michael Berry
Ngozi Ezike? Claudia Grossmann? Steve Hinrichs?

Steve Hinrichs
Good morning, I am here.

Michael Berry
Jim Jirjis? John Kansky?

John Kansky
I am here.

Michael Berry
Bryant Karras? Steven Lane?

Steven Lane
Good morning.

Michael Berry
Nell Lapres?

Nell Lapres
Good morning.

Michael Berry
Les Lenert?

Leslie Lenert
Present.

Michael Berry
Denise Love? Arien Malec?

Arien Malec
Good morning.

Michael Berry
Clem McDonald? Aaron Miri?

Aaron Miri
Good morning.

Michael Berry
Larry Mole?

Larry Mole
Good morning, sir.

Michael Berry
Abby Sears?

Abby Sears
Good morning.

Michael Berry
And, Sheryl Turney?

Sheryl Turney
Good morning.

Michael Berry
Good morning, everyone. Thank you, and I would like to now turn it over to our co-chairs, Carolyn and Janet, for their opening remarks. Janet? Carolyn?

Opening Remarks (00:02:28)

Carolyn Petersen
Good morning, everyone. It is great to see everyone back for another meeting of our task force today. As you know, we have quite a lot to cover in a short time. We hope to work today very effectively by reviewing on slides some of the feedback that we have received from you in the homework so far, and then to pull up the crosswalk and start talking about how that feedback translates into recommendations that we made to ONC as our final work product for this task force.

I appreciate all the feedback that we have received so far, and I want to let you know that because we are adding volume with that, in the coming weeks, we will be sending out Excel spreadsheets that include all of that feedback that you can use as you review the recommendations and think about how you might want to change them or what might need to be added or revised just to give you a heads up. So, if you have not yet had a chance to log into the spreadsheets and submit your information, please go ahead and do that

this week to get us caught up and so that we can really operate from a comprehensive information and knowledge base. Go to the next slide, please.

We will start by reviewing our charge, and then, Janet will share some remarks and lead us through the preliminary feedback. If we could have the next slide, please. So, again, here is our charge. I will read it for the benefit of our members who are just on the telephone and for the public. "The task force is here 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. The task force has two priorities: First, to identify and prioritize the policy and technical gaps 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. And also, the task force shall identify characteristics of an optimal future state for information systems relevant to public health and their use." And, next slide, please. Now, I will pass the mic to Janet for her opening remarks, and we will get into the feedback. Thank you.

Review Surveillance Discussion Guiding Questions and Draft Recommendations (00:05:18)

Janet Hamilton

Great. Thank you so much, Carolyn, and I will just comment that I am not seeing text displayed on my slide, so I hope others are able to see that. I will just echo for opening remarks that we do have a lot to get through in a short amount of time, and I think we have appreciated all of the feedback that we have gotten thus far, and in an effort to be more efficient, we are going to be structuring this to review slides with some of the feedback that we have gotten thus far and summarizing that, and then, from there, moving in to the new discussion topics, which, today, will be focused on lab.

So, I am still not seeing the slides, but I do have them pulled up in a separate space, so I will be navigating these, but I hope we can stay on the same page together. So, I am looking at Slide 7 now, and this slide is related to discussion that we had previously around key surveillance use cases and identifying what major gaps exist in health standards that prevent data from flowing between clinical and public health entities. I think one of the challenges that we did have as a group was really trying to be broad and deep at the same time, so these surveillance use cases are for large surveillance use cases around testing, case reporting, syndromic surveillance, and immunizations, and I think what we have are broad comments, and we hope to spend a little bit more time, as I mentioned at the outset, getting a little deeper in this space, and so, today, we will be focusing in more on the laboratory piece.

But, these are the things that were identified during our previous meeting. Lack of adherence to standards that are existing: We have seen a lower uptake of some of the newer standards, such as electronic case reporting, as well as a lack of certification requirements within EHRs. There is confusion over different reporting standards across jurisdictions about knowing what to report, when to report, and how to report. When reports are made, there is often missing data in those reports, and that is a result of multiple causes, including that standards really do not address completeness or timeliness. There are duplicative and misaligned reporting requests, which can add to provider administrative burden, and I think also ties into the bullet around confusion, and then, I think another thing that was very clearly brought out was lack of incentive to really move adoption forward in a meaningful way. Next slide, Slide 8, please.

So, here, we are looking at real and perceived barriers that continue to inhibit progress, integrating multiple public health social services and clinical data sources when responding to public health emergencies, and those things that were identified in the meeting as well as in the homework were a lack of patient identifiers and ability to link patients across clinical settings and public health, and I think specifically, there is no single patient identification number, and then, when we do get reports, they are often missing patient identifiers.

Current processes to set up data exchanges are time-consuming for both providers as well as public health to test these new interfaces, and that onboarding ramp takes time and resources and needs simplification. Lack of centralized national infrastructure can also lead to duplicative and confusing reporting data flows and requests, so not only have there been data requests by state and locals, but also, in this response, data requests at the federal level, which has led to additional confusion. Lack of clarity on how to best protect patients' privacy while promoting interoperability: We heard very strongly this issue around lack of consistent funding for public health infrastructure and that previous funding models have been rigid, often disease-specific, and cause multiple problems, including data silos and lack of interoperability. There is provider and administrative overload, perceived lack of value in data and reporting, lack of consistent HIEs and capabilities within those HIEs to support public health reporting, lack of standards describing SODA and where SODA data could be collected, and of course, differences in social service and data systems creating difficulty in connecting public health and the clinical **[inaudible] [00:11:26]**.

Okay, so I am still without slides in my presenter view, so I am going to move on to Slide 9, and this is feedback on what real and perceived barriers exist to continue to inhibit progress in integrating multiple public health, social service, and clinical data sources when responding to public health emergencies. Actually, this looks… So, same topic. This is addressing now from a policy and licensing and legal perspective, so we have seen…

And, I think the comment was brought out very strongly that there is a lack of recognition that public health is part of healthcare. We have often viewed these separately, and that has led to many of the challenges that we have today, a lack of alignment in jurisdiction versus state versus federal privacy and security laws, and a lack of clarity with HIPAA on data sharing for public health purposes. For example, "minimum necessary" can often lead to differing interpretations, and those occur at the state and local levels. Again, a lack of adoption of incentives for public health data sharing, and specifically public health data sharing across states as well. Again, we are seeing the lack of funding for public health overall, and then, there are instances where we also see lack of federal guidance and restrictive laws on data sharing at the state level that often prevent certain types of data sharing and prevent data sharing between states and the federal level.

We also see, brought out from a patient privacy and digital access as well as social justice standpoint, again, issues around HIPAA with the current use cases, challenges with FQHCs and individual providers often lacking resources to establish the key public health connections, and then, a lack of transparency about how to protect health information geolocation and how that is collected, used, and stored.

And then, to summarize for Slide 10, what real or perceived barriers exist as it pertains to this same topic, public health, social services, and clinical data sources, when responding to public health emergencies, but specifically addressing gaps and barriers on federal versus state and local sharing. So, again, we brought

up strongly variability in local jurisdiction and state reporting requirements and capabilities. We do not have the same sets of capabilities across the country, lack of agreement on a minimum necessary data set that would meet both state and federal surveillance goals, lack of standardized patient identifiers, and the inability to leverage federal funding of social service programs to adopt standards and technology compatible with public health.

I realize I am moving through these pretty quickly, but we have a lot to get through today. So, Slide 11 focuses on issues around health equity and surveillance systems. The question that was posed to the group for discussion as well as included in the homework for feedback would be how do we ensure that surveillance systems adequately identify potential sources of bias and health inequity to address issues around health equity? And, there were several gaps that were identified here: Again, lack of adequate standards that address the collection of this, as well as…

We see gaps that do not require certain kinds of data to be collected as well, such as gaps in things like disability information, race, and ethnicity. They are often outdated or ineffective processes for collecting this data. I think we can recognize that there have been, for many years, established five different race categories and two different ethnicities, but that does not necessarily represent how people identify themselves in these categories, which can lead to challenges in actually collecting the information at all. And then, really, again, lack of funding coming out very strongly for underserved areas and the inability to consistently include those with poor access in healthcare and surveillance activities.

In terms of gaps identified for streamlining data sharing and asking the question about what, if any, work would be needed to ensure accommodation of individual desire for and right of access to protected health information, we identified as a group lack of privacy regulations that promote data sharing between social service and public health, and that in the absence of regulations that promote this data sharing between public health and social services, we really need to ensure that there are consistent electronic pathways that allow that data sharing to occur, specifically related to GIS data and different types of patient or population movement data. There is a lack of public health actually being able to tap into that to determine where service gaps may exist and use of GIS data, and then, a lack of standards, again, to link public health data to social service data.

Finally, around case reporting, I will highlight that we did not specifically address this question during the discussion the last time, but it did come out in several of the other questions, and then, we did get some feedback from the homework, so I just want to be sure that we recognize that this did not fully get discussed the last time. Specific to case reporting, the question was how we can reduce the manual public health reporting burdens for providers across the care continuum and support services. Are there steps and incentives that are needing to scale automated methods of case reporting, such as electronic case reporting?

And then, in three bucket areas, the first being hospital or provider networks, and as identified, one of the activities was to promote EHR vendor adoption of standards that do promote interoperability. For long-term care and support services, it was identified that there needed to be improved funding for EHR adoption in long-term care and support services and that case reporting was an activity, as well as to include incentives for adoption of other related standards, such as electronic laboratory reporting, syndromic surveillance, and immunization registries, and then, for community providers, the need to include incentives and funding for

standards adoption there. Okay. So, I am going to stop here, because I think that reflects the discussion that we had previously, and see if we have comments here, and then, after we have some opportunity for comments and discussion, into the laboratory reporting and lab issues, which we want to really focus on today.

Bryant Thomas Karras
Janet, this is Bryant. My tremendous apologies, I hope you will forgive me. In five minutes, I have to drop to do a talk at the Bill and Melinda Gates Foundation. I have some prepared comments that I will send you via email.

Janet Hamilton
Okay, that is great, and…

Bryant Thomas Karras
Related to the ELR and challenges that we face.

Carolyn Petersen
You can also post those in the chat, Bryant, and then, everyone will have the benefit of them now.

Bryant Thomas Karras
Great, thank you.

Carolyn Petersen
So, I see that Clem's hand is raised in the Connect, so let's start with Clem, and then we will have comments from Jim Jirjis. Go ahead, Clem. You might be muted.

Clem McDonald
No, I was muted. I have a number of suggestions and thoughts. One is I think we have too many things and it is too diffuse. I think we have to focus down a little bit. Some of it is redundant and repetitive, and we will not make an impact. In terms of patient identifiers, we are screwed. There is a federal law against it. But, there are a couple of surrogates. Medicare now has a unique identifier for all of its aged patients, so we can at least take advantage of that, and maybe take advantage of the other insurance ID, though it will not work as well. That is just a thought. The issue about sending complete patient information in the laboratory has got some promise. I think some of it is related to privacy. They just send the accession number off to some distant lab, and whether that is because they cannot carry the information, that needs to be investigated as to why, whether there are some deep problems, and why they do not send along the patient registration record when they make the request to referral labs.

The lack of standards is not fair. I think mostly, it is lack of use of them or lack of understanding of them. The standard messages about lab tests could be sent anywhere. It is just a matter that many have receivers. I think many of the smaller public health departments do not have the resources to accept electronic things, so that has to be a priority somewhat. And then, the third thing is that public health and clinical care do not understand each other. So, what happens is the burden on physicians comes badly because public health is asking a lot of questions the physician maybe cannot answer well, or, if they were asked differently, they could have sent a surrogate that would have handled it just as well.

Finally, they should not ever ask physicians' offices to report stuff that the referral labs or commercial labs know and would have sent already. So, I just think there should be more dialogue between the two sides to understand the issues and not just be demanding and saying, "You have to do this" without thought about how else you might do it. That is all I have.

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

Jim Jirjis
Wonderful summary. I agree with the different points, but I wanted to make sure that some of the things we had talked about in the past and that I and maybe others had submitted in the survey made it in, and here they are. There are three or four. First, I do not know if we call out more the costs of this point-to-point interface approach, or even if people adhere to standards, et cetera, such as the contracting, the testing of interfaces, and the maintaining of them. I hope we can call out more that under-unifying infrastructure for this and the others to simplify for the different stakeholders so that we are not landing in a world of everyone doing point-to-point.

The second is just calling out… I think you have "lack of adherence to standards." I just wanted to emphasize that. But, coupled with that, it is not just about adhering to standards, it is the tremendous variation in the implementation of those standards and interfaces that leads to all kinds of costs. So, I think calling out implementation guides, et cetera is important. And then, the last is for this and the other categories. I think you have incentives in there, but making sure that the incentives include all the important stakeholders, not just one or two, not just providers, but also public health, PPE suppliers, labs, et cetera. So, people will be incentivized to use standards and have implementation guides and processes, and then, hopefully, all of that being done in a way that avoids a gazillion point-to-point interfaces that are highly costly to all involved.

Carolyn Petersen
Thanks, Jim. Let's go to Denise Love. Denise, you might be on mute. Okay, it seems like we are having some audio difficulties with Denise's line. Let's go to Steve Eichner.

Steven Eichner
Thank you so much. I have a couple points. One of the things we need to consider is how information is being routed to public health and thinking about some of our data quality issues, like race and ethnicity or other missing data. It is really not in the business interest for some laboratories to have information about whether I went to Aruba for travel last month or not. If we can simplify or change the routing so that the "ask on order entry" questions and similar data is collected after the laboratory result is provided, you might be more efficient and reduce laboratories having to invest additional resources to store information that they are really not doing anything with other than storing it forward to other destinations.

In looking at the rules of HIEs and costs of onboarding and exchange, I think it is important to understand that there are two different components of that cost, one looking at establishing a basic connection, whether it is VPN, or SFTP, or a web service, or whatever on that level. We spend much more of our time and effort on ensuring that the quality and the content of the message coming across that connection is meeting

public health's quality standards, so I just wanted to tag out that that is a burden that still exists, regardless of the number of connections any provider may have or may need to maintain. Just pulling that apart becomes relevant as we look at the costs of connectivity and **[inaudible] [00:27:52]** efficiencies in connection and overarching costs in validating or establishing those connections.

Additionally, looking at health equity, I think it is important that we address race and ethnicity issues. We also need to be sure that we are addressing disabled and other types of equity issues across the board. Right now, if there is a disability question asked, it is usually "Are you disabled?" without any subsequent information, and that really does not get to the heart of the issue or really help address some of the gaps that folks have. So, I think we have a lot of opportunity, and the summary comments are really good in addressing a lot of it. Thank you very much.

Carolyn Petersen
Thanks, Steve. I just want to clarify that we will be moving into some new material today, so we are going to take a couple more comments and then go forward. Let's go to Arien Malec.

Arien Malec
This summary is absolutely fantastic. One additional point or maybe elaboration of a point is that public health data systems are going to be best run when they build on top of a broader interoperability infrastructure. So, historically, in the worst case, public health has adopted very specific or bespoke interfaces. The classic example of this is the reportable conditions specified CDAs that called for very specific information for reportable conditions, but was not flexible in the field. The new approaches, particularly ECR and ECR Now, which build on top of HL7 FHIR and are trigger based, are much better approaches because they build on top of a broader infrastructure interoperability evolution.

So, to the extent that we can have interoperability evolution that benefits the whole health system and benefits public health, public health is going to be better off. Another example of this is that I do not know that anybody would have connected improving the orders/results interface for clinicians with public health, but if you look at where the breakdowns were in ELR, by and large, it was in labs that had no access to demographic and contact information. If we start thinking again about these flows as a system and build benefit for all the actors, which builds benefit in this case for clinicians doing orders electronically in a bidirectional way that is standards-based, we can build on top of that infrastructure for building better public health. So, it is an interoperability flavor of the basic point that public health is healthcare, and it is healthcare of populations in the broadest sense. We should also think about the public health data infrastructures as being interoperability and built on top of the interoperability we are also using to improve individual care episodes. Thank you.

Carolyn Petersen
Thanks, Arien. We continue to have trouble with Denise's audio, so I think at this point, we are going to move forward with a new discussion. Janet will pick that up. I see that there are some other hands raised, but I think in the interest of being able to get to our new material today, we will hold the discussion for now. Thanks.

Janet Hamilton

Great. Thanks so much, Carolyn. So, again, we wanted to focus our new discussion today on lab, and I fully recognize that even in reflecting on the overview of what we have heard that we have already heard comments specific to some of the issues that are raised and specific to lab. I think the way that we will take this is to go question by question, and so, we may need to truncate some of the conversation in order to get to the questions themselves, and again, recognizing some issues that are on these slides that have already been brought up in the conversation, and we appreciate folks who submitted their thoughts in this during the homework, so we are looking forward to refining these, and maybe getting towards Clem's comment that we were a little broad before, so now, we are going to focus down on in.

So, specific to labs, the question up for discussion is during COVID-19, what were common themes encountered that impacted the timing and completeness of COVID-19 result data reported to state and local health departments? And, issues that have been identified for discussion and refinement include missing demographic data, incomplete or uncollected information leading to incomplete data when reporting to public health, inconsistent capture of residency information, particularly those with housing instability, delays in test turnaround time to inform patients and patient results information, as well as delaying the data getting to public health. COVID-19 test orders required many data points to be entered, often manually, by ordering providers, which led to some increased burden, and as we just heard Aaron make in some of the comments, the order interfaces were not set up to easily pass info between the EHR and the lab order system.

Lack of HL7 and standards adoptions amongst labs: There were many new laboratories that came on. Many of them had never reported before to public health and were not familiar with the HL7 standards. Lack of incentives to support reporting at all, to support reporting timeliness, so, even if there was a standard, no incentives that indicated how quickly reports should be made or how complete the data should be when reports are made. Again, barriers in matching records from case reports and laboratory results. Many new providers, different, nontraditional testing locations, and patient forms requested to be filled out at the time of testing were often missing key demographic fields, not allowing the patient or the provider to ever complete them themselves, and then, a lack of patient opportunity or engagement to provide the demographic information at a later date, for example, when retrieving their test results, et cetera. So, I will stop here with this information and look forward to the discussion.

Carolyn Petersen
Task force members, if you could please raise your hand using the Adobe Connect tool, we will get on to the laboratories and EHR discussion. Abby Sears, go ahead, please.

Abby Sears
Thank you. I think it is a great list. I am just going to bring an example of what we struggle with with our patient population. We have a higher rate of testing positive and/or needing to move data for contact tracing, and our patient population has the highest rate of erroring out based off of patient matching, so we have very complete data, but we cannot get it matched effectively, and I know that we are already discussing the importance of finding an algorithm, but I just want to reiterate from an equity issue the importance of that in the process, and then, reinforced using national frameworks because it is really incredibly important that those standards are being supported and shared.

Carolyn Petersen

Thanks, Abby. If we could go to Danielle Brooks, please.

Danielle Brooks

I was on your mind, no worries. I had raised my hand. I agree with the previous comments in terms of making sure that it is considering the equity issues. I am not sure this is the right place, but one thing I have noticed that is missing from the broader conversation is the consistency of capturing language data. So, while we have talked a lot about demographic data, particularly race and ethnicity, language has been left out, and why that is important as we look at this communication information, patient privacy and that kind of information, and also understanding those key pieces about language needs and language access that actually helps facilitate public health messaging and downstream impacts of making sure they are actually getting to the people in a manner that they understand the most. So, I would encourage us to think beyond the demographic component and also **[inaudible] [00:37:44]** that communication aspect because it is such a tie-in to making sure that individuals can properly consent, and also, things are expressed to them in the best **[inaudible]**. Thank you.

Carolyn Petersen

Thanks, Abby. Let's go to Steven Hinrichs.

Steve Hinrichs

I want to affirm all the items that are on the list, but also call attention to the importance of unique identifiers, and that is critical when we begin to look at the over 750 million COVID test results that went through our systems and the need to deduplicate, and if we do not have a unique identifier at least at the state level, it will be very difficult to make sense of all the results, many of which have been duplicated by repeat testing. Thank you.

Carolyn Petersen

Thanks, Steven. I see Denise Love has gotten her audio system working now. Denise, please go ahead.

Denise Love

Well, this may derail this conversation, but I am trying to figure out where the pain points are and where the best places are to capture the nonclinical data more upstream rather than every lab test and every visit because I just see a lot of pain points and I am not clear how that would work, so that may derail the conversation, but I just wanted to register my confusion.

Carolyn Petersen

Thanks. And, Clem, I see your hand is up. Go ahead on laboratories and ELR.

Clem McDonald

Yes, thank you. I think we have to separate the issues that are technical and solvable by technical means from those that are not. We cannot change the lack of an identifier yet. We should lobby, and maybe we could, and there is some slight movement toward it. The issue about catching demographic data goes way deeper than standards. It is that people will not say it. Either the clerks will not pick it up or the people that are coming to the front door will not pick it up because they are from other countries and they do not understand what the different racial categories mean. I do not know we can solve that. They are in the standards; they have always been in the standards, and at our hospital when I was working in the inner

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city, about 30% of the racial data was consistently missing. So, it is not a technical problem, but it is important. I just do not know how we are going to solve it. That is all, thanks.

Janet Hamilton
Clem, this might be an area for others to comment on and drill down into more, but I think one issue is that it does not get asked, but I think we also really identified in the pandemic that even if it is asked at one point in the process, for example, in the patient encounter, the order process is not moving that data over, so when an order is placed through an electronic order interface, even if the data was captured within the electronic health record, it is not being moved over into the order, and so, then, when the lab result is received by public health, the data is missing because it was never received by the laboratory.

Clem McDonald
Well, that is a deep problem, and we should investigate it a lot because the V.2 specs say the registration record goes with the order, so why that is not happening and whether it gets dropped somewhere along…
I still worry that people feel that is privacy information and they cannot take it in the order. We need to understand why it is not happening because it is a standard part of the V.2 spec.

Carolyn Petersen
And, let's go to Danielle Brooks, please.
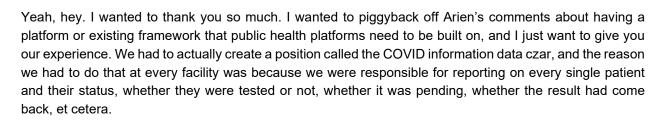
Danielle Brooks
Sure. I wanted to address Clem's comment, and I saw some **[inaudible] [00:42:09]** attached. It is not necessarily an understanding issue on the consumer side per se. The way that the processes and the best practices have been set up, they are inconsistent across not only markets, but within health systems themselves. There have been practices where individuals are allowed to estimate a person's race or ethnicity based on anything from a last name to an appearance, and so, part of the reason why this demographic data is so incomplete is because the standards are not there. It is also not an issue of privacy concerns per se, it just takes a little bit of additional information to explain the rationale, and also, the way we are ordering the questions.

So, for example, we know that from a pretty much factual matter, if you ask somebody their ethnicity, you will be able to ascertain those demographic fields a lot better than just going to a standard OMB category, so I would actually argue the rationale while demographic data is so difficult…well, I would not say difficult to collect, but incomplete, because 1). There is no standardized way of doing it, 2). The current categories are insufficient, and 3). We need to make sure it is operational as well as making sure we are informing the consumer as to why. And so, I would really challenge our thinking around that because I think it is, again, coming back to really making sure we are creating that standardized process because I think it is more incumbent upon our work to make sure that is consistent, and learning from those past mistakes and realizing that there is a very strong and very expert way of moving forward.

Carolyn Petersen
Thanks, Danielle. And, I see Jim Jirjis has his hand up.

Jim Jirjis

Yeah, hey. I wanted to thank you so much. I wanted to piggyback off Arien's comments about having a platform or existing framework that public health platforms need to be built on, and I just want to give you our experience. We had to actually create a position called the COVID information data czar, and the reason we had to do that at every facility was because we were responsible for reporting on every single patient and their status, whether they were tested or not, whether it was pending, whether the result had come back, et cetera.

And, the reality is patients would come to our hospitals either to be directly admitted, come through the ER, and if we tested them, it was one issue dealing with the labs to give us results back and not adhering to standards, where we had to actually map all that to value sets before we could actually report. But, I am talking about even upstream from that. We had patients come in who may have been tested in an outpatient clinic. Maybe they were tested in another hospital. Maybe they went to public health. And, we had to have this information czar actually figure out where each patient had the test, call them to try to actually get the results, often verbally on the telephone or on a fax machine, let alone…

So, there is an enormous delay and burden, and even figuring out where the patient had data and had pending or results of their COVID test, let alone get them in a machine-understandable way that could automate reporting. And so, I say all that because of a record locator, for example. So, when a patient arrives at a particular provider, there ought to be a record locator service that understands where the patient has been and can automatically get standard-compliant information immediately into the data system for providers so they can immediately report. That will reduce the burden on the provider cost-wise and on the lab testing sites, et cetera. It just multiplies the cost. It will reduce the delays in actual reporter. So, it is a confirmation of Arien's comment about there being a platform. That platform ought to have a record locator so people are not trying to figure out where patients were tested.

Janet Hamilton
Great, thank you. Go ahead, Carolyn. I am glad you are back.

Carolyn Petersen
No, go ahead. I am still trying to get Connect to go forward.

Janet Hamilton
Okay, we are having technical problems, so Carolyn is getting back with her excellent moderating skills. Next is Les Lenert.

Leslie Lenert
Hi, yes. It seems like we do not really have a technical issue here. What we have is a lack of incentives to align the systems, and that what we should be suggesting or exploring at this point is how can we incentivize the healthcare system to provide ELR messages that are validated and accurate and that contain the unique identifier for the task, the unique identifier for the facility, and, dare I say, a unique identifier for the patient, however that is constructed? Without the right incentives, we are not going to get to that program point, so how do we… That is what is really needed here because we have the technology in place for all of this right now. It is that there is nothing that there is nothing really encouraging people to deploy it.

Janet Hamilton

Les, can I just push you a little bit on that? Do you have thoughts about what that might be? Or, others? I am just asking this because we have heard "lack of incentives" as an umbrella.

Leslie Lenert
How about a meaningful-use-like program for public health data contribution for healthcare providers? That could be a positive incentive. Or, a Medicare penalty program for providers who fail to produce ELR messages that meet certification standards. If their EHR cannot be certified to meet the standards, then there would be a penalty. So, we have seen this as incredibly effective at getting the healthcare system to rally around it, both by incentives and penalties, but if we are going to spend a lot of money, that might be the way to spend it.

Janet Hamilton
Okay, great. And, others might have some comments on that. Next, let's go to Abby. Abby Sears?

Carolyn Petersen
You might be on mute, Abby.

Abby Sears
Yeah, I did not raise my hand, sorry.

Janet Hamilton
Okay, I apologize. It is raised in my view. Okay, next, I see John Kansky's hand raised. John?

John Kansky
Yes, thank you. A bit of a cross-cutting comment. So, thinking about the incentives issue and policies we might use to address some of these problems, and thinking about some of the problems that I identified earlier, I think when we formulate recommendations, we may need to address a big issue, which is do we… Let me try to be a little more articulate. If every state had a statewide health data utility or a health information exchange, that would be an approach that, if these incentives were in place, could lower the burden of implementing them because in many places, they already exist, in some places, they do not, but if we set a policy path towards every state having that health data utility, that would be one approach with some gaps to fill.

If, on the other hand, we are going to rely on national frameworks or a central, federal-government approach with each provider using their electronic health record and standards to report directly to some centralized system, those are completely different approaches, and the reality, as we have seen in our current, imperfect, but sometimes relatively effective interoperability ecosystem nationally, some combination of the two is the best to give providers and states the flexibility to achieve the goals that we want. So, I just wanted to acknowledge that we may need to make some recommendation about whether it is one way, another way, or the flexibility to allow different approaches. Thank you.

Carolyn Petersen
Thanks, John. Clem, I see your hand is raised. Did you have one more brief comment?

Clem McDonald

Yeah, it is regarding the point-to-point messages. I think a number of you made the point that if you connect each place independently, it is gigantic. It is an exponential workload, and somehow, you have to avoid that. John highlighted the two points. Honestly, I think health information exchanges have been underemphasized as existing opportunities to make this a lot easier, but then, you would like to have the directions. They do go to public health from the health information exchanges in many cases, but allow other kinds of places to join in if they are held back by regulatory or other barriers. But, because there are so many of them working now, I think we can make the biggest progress if we can emphasize them more, especially for the public health usages.

Carolyn Petersen
Thanks, Clem. It looks like we have no more hands raised, so with that, I think we will continue on with the discussion. I know we do want to at least start taking a look at the crosswalk today, so I will hand the mic back to Janet.

Janet Hamilton
Okay, great. Thanks, Carolyn. Let's go on to the next slide, and this is the last slide, and then we can look at the crosswalk as well. I will say there have already been a number of these things that have been identified. So, thinking more specifically about what factors impact the timeliness of test reporting, how can the timing of reporting be improved? And, people may have some thoughts specific to the improvement. What we got a lot of feedback on in the homework were the gaps. So, again, maybe folks want to think of suggestions here. So, gaps that were identified were delays in result reporting due to batch reporting, missing demographic data, a lack of electronic orders, lack of incentive to adopt standards necessary for data sharing, delays in lab test site onboarding, in part due to code mapping activities and in part due to…they were naïve in terms of their ability to support HL7 standard messaging, uncertain about who met which testing criteria to report, and then, of course, manual reporting and mailing of records. So, again, those are really gaps, but if folks have additional suggestions on improvements of the timing of reporting.

And then, the other question for some additional reflection is when are common data quality or completeness issues encountered? How do these data quality and completeness issues impact the public health response? And, I think maybe for us to focus on more are what are some of the mechanisms for systematically avoiding and addressing these issues. And again, we have already heard this come out in our conversation, but I will say missing demographic data, missing information on deaths, county and ZIP code, comorbidities, testing guidelines, maybe "ask on order entry" questions, lack of consistency exchanged from the electronic health record to public health, and organizations not consistently seeing the data that they are sending in terms of getting feedback about data quality issues or missing information so that they could independently course-correct. So, we will see if we have any comments on these.

Carolyn Petersen
Do we have any task force members on the phone who have comments? I know you do not show up in Connect, and I want to make sure we do not miss you.

Jim Jirjis
It is Jim. I am raising my hand.

Carolyn Petersen

Okay, Jim. Let's go with you, and then we will go to Steve Eichner after Jim.

Jim Jirjis

On the last bullet, we ran into this quite a bit, where we were submitting data, but because we did not have confirmation of what was received, not just at the public health department, but also for the federal government's grading of us, we began to hear that even though we were 100% compliant on all fields, our hospitals were only reported as being compliant for seven days out of that month. So, when we dug in, what we found was there were rules behind whether the state reported or we did that were incorrect that were actually negating our complete submissions because the state was reporting in an incomplete way. We had no insight into that, and so, I want to really call out the last bullet that when submitted, there ought to be a confirmation of receipt, and then, when there are multiple intermediaries, we ought to have insight into whether data is being lost along the way.

Carolyn Petersen

Thanks, Jim. Let's go to Steve Eichner. Steve, you might be muted.

Steven Eichner

Sorry about that. I think part of the issue is having standards that support the data that we are interested in and being able to communicate those standards in an efficient and timely manner. This certainly presented some issues with COVID-19 with the necessary data elements being created on the fly, and even some problems in terms of getting the data incorporated into HL7 messages. We can also improve the routing of reporting to take better advantage of health information exchanges and other resources to include some of the nonmedical information, some of the demographic fields to get populated, perhaps in other ways.

What happens if we push some of the reviews for data quality further to the provider in terms of leveraging things like RCKMS to do a quality check to ensure, at least, data completeness at the provider level, then getting to public health, and a response for additional information taking two or three days to get back to the provider because there is a missing field. Can we alter how we are doing it to do some of those basic error checks at the provider end without creating an additional burden on the provider to make it easier for more complete information to be reported? Thank you.

Carolyn Petersen

Thanks, Steve. Let's go to Abby Sears.

Abby Sears

Thank you. I think my comments are in here, but I want to pull them out and tease them out a little bit just to make sure that they are clear. What we had issues with, again, were the matching algorithms. We need stronger matching algorithms. I do not have an answer to how, but if we cannot match the data, it errors out and does not move at all, and our error rates were upwards of 30%, and that is almost all naming nomenclatures of culturally different demographics.

So, the second issue that we had was even when our data did move, the states were requiring manual data entry and did not have the ability to pull down that data into their systems, and so, once we are doing manual entry again in some states, even though the data has moved, then there are challenges with data integrity and data quality in that environment. I think that is in here under "manual reporting," but I just

wanted to call it out to make sure that we are finding ways to resolve those issues, and I know that part of that is the funding mechanisms and making sure that our infrastructure and our public health environments are modernized, but when they are modernized, we have to stop with the requirements of manual entry as well because they do not feel comfortable with what they are getting from the national frameworks. We have to incentivize the use of the most efficient ways to deliver that data.

Carolyn Petersen
Thanks. And, let's go to Steven Hinrichs.

Steve Hinrichs
Thank you. In regards to the timing of reporting for improvement and also the issue of mechanisms for avoiding the problems we have outlined, others have mentioned this, but I want to say again that there are technical solutions that are available, and they do work, and I particularly want to cite the example in the latest outbreak where APHL helped in the development of algorithms for automatically identifying case reports and calling out both Cerner and Epic for willingness to participate and implement those algorithms, and they had major impact and were very successful. Thank you.

Carolyn Petersen
Thanks, Steven. And, I see Clem McDonald's hand up. Go ahead, Clem.

Clem McDonald
[Inaudible] [01:01:51] they are saying I think there was trouble with matching, and I assumed that was patient matching, but then she wanted to talk about racial codes, so I think clarity on what is being matched is important. I think the last speaker was talking about matching patients. Could I get clarification on that, that the Cerner and Epic algorithms were actually patient-matching algorithms?

Steve Hinrichs
That was the individual before, and I think they were talking about patient-matching algorithms. I was talking about case identification algorithms.

Clem McDonald
But, does that not depend on patient matching?

Steve Hinrichs
It depends on what you mean by that.

Clem McDonald
Well, I think we ought to get clear on what we all mean about all this stuff. But, if you get a case that comes in, and one case was John Brown, and you match the case to the same place and the same time, but the other case was Mary White, it has gotten them, so I am assuming you have to get the patient first, but please help me with that.

Carolyn Petersen
So, it looks like this is a point that… Janet and I can frame questions that go out with the homework. Hopefully, we will get some feedback that will help us crystallize this a little bit more. I know that we did

want to get to the crosswalk at least a bit today, and we have our public comment coming up in about 10 minutes, so I think we will hold on this discussion and see if we can have a more focused, clearer question to address in a future discussion.

Clem McDonald
Okay.

Carolyn Petersen
Let's bring up the crosswalk on the screen, and I will give you a bit of an orientation to this piece. What we have been accumulating through our last couple weeks with the homework and also these discussions is some feedback about where we sit with some of these questions that ONC has asked us to debate in our meetings. We now need to coalesce all of that information into some recommendations that this task force can agree upon so that Janet and I can present those at the full HITAC meeting preliminarily in June, and then to get a vote on the final recommendations at the July HITAC meeting. So, we need to keep moving quickly.

The crosswalk is a tool that we have used previously in other HITAC work to bring in line all the bits and pieces of information that we are contributing to try to add those up into more specific recommendations that we can make for the national coordinator. The way we organize that, if you can see on the slide now, with this crosswalk is to identify the topics in the left column, to briefly state the gaps and the problems or specific issues that are being addressed or that we need to think about in this topic, any opportunities that we are aware of, which can be tools that some of you have mentioned or ideas about other actions that can be taken that will support getting to a resolution for the topic, and then some recommendations that we can make based upon what we understand about the gaps and any potential opportunities that we have identified.

So, in coming weeks, as we review this information, Janet and I will be working to align your comments and your homework into these recommendations, and then we will be looking to refine these. We will also be sending out links to the Google docs where we ask you to go in and make edits or comments and help us to firm these up and get them to places where the task force can vote and feel comfortable that it really is our broad recommendation rather than something that just one or two of us feel strongly about. So, it is a distillation process.

Today, we wanted to orient you to this document because clearly, being that we have just an hour and a half a week to talk, we probably will not be able to discuss all the recommendations and all of the questions to the detail that some of us might like to do in ways that we would proceed with other organizations. Our deadline in July is really a hard deadline in that ONC needs to feed this back to HHS for its deliberations, so we are continuously thinking about how to bring your good perspectives into something we can take forward to the national coordinator. Do you want to review any of the specific points in these pages, Janet? How would you like to go forward getting us started on these?

Janet Hamilton
Thanks, Carolyn. I just wonder… So, as you all can see, we have six pages of the crosswalk, so we have been working to coalesce the different information, and we have been dividing them up by the topic area, the gap, the opportunity, and the recommendation. I think one thing, and it is usually true that this happens,

is that it is easier to identify the gap and a little harder to really come up with the recommendation, and so, we want to encourage people to really focus as we look at this going forward on not just stating the problems, but really trying to be thoughtful about potential recommendations.

So, maybe it is worthwhile to just walk through what we have already seen in terms of topic areas, and then, I can see a number of hands raised for thoughts as well, so, as you can see, we have started grouping the different topic areas. So, we have syndromic surveillance, electronic laboratory reporting, improved funding, formation of a standing public health work group, major gaps in standards adoptions for key use cases, and if we scroll to the next page, here, we see technology and infrastructure factors affecting key surveillance use cases again.

Here, you will see, in terms of topic areas, the patient privacy digital access, social justice factors affecting key surveillance use cases, policy, licensing, and legal factors, federal/state/local factors, health equity, enhancing data sharing between public health and social services, which is really breaking up the different questions that we have posed over time, streamlining data from large hospitals and provider networks, long-term post-acute care, and engaging community providers. And then, we had the other topic areas, which we have not really gotten to for fleshing out. So, I think in the interest of time, let me just stop here because I see we have a number of hands raised and some thoughts about this. We have not heard from Jim Daniel at all, so let's start with Jim.

Jim Daniel
Hi, Janet, thanks. Can you hear me okay?

Janet Hamilton
We can.

Jim Daniel
I was looking at this, and I was thinking a lot about what is going to make sense for the people who get the recommendations, and I really like the way that you framed today's discussion around a specific topic, like ELR and the details, and I think because systems are so unique, recommendations should be by system as well. So, if we think about the core public systems, such as ELR, immunization, syndromic, electronic case reporting, there are some core recommendations that we can make in each of those areas, and we can follow a template for each one. I am just going to go over what I think those things would be at a super high level.

The first thing, which is something that I think we have not done and that is important because it is part of the executive order, is that based on what we have learned from COVID and what we knew from Ebola and Zika, we need to describe the ideal business case. What should be happening completely from a business perspective? Let's forget about standards and technology. Let's describe the data flow and what should be happening for each of these systems. I think we should be doing that from the perspective of the jurisdictional health department, the provider, the payer, the laboratories, and other stakeholders. It will depend on which system we are talking about, and other stakeholders might be important, but I think we need to describe that ideal, forgetting about the standards. That is something I do not think we have done.

Then, I think we can start putting some of the other stuff that we have documented already into a template that talks about the current technical barriers, the current policy technical barriers, and how we get to that ideal. What are the standards? What does the EHR have to do? What does the public health receiver have to do? And then, what are the incentives to do this? I think that kind of framework gets us to a better sense where it is clear to the federal government what the kinds of things they can do are to change and actually make this happen, and we also have that clear business case of how things should be flowing. I think it is clear in all of our minds, and everything we are talking about is assuming that ideal data flow, but we have to describe that so that it is clear to everyone and we all agree on what that is.

Carolyn Petersen
Thanks, Jim. Let's go to Aaron Miri.

Aaron Miri
Thank you. All right, so, I want to take a step up a little bit. I think we are all focused on and talking about the same things here, and I completely agree. There is a need of adoption of systems, and funding, and standards, and so forth and so on, but let's go back to last year of what happened. As this rolled out, as we started determining what lab tests could actually be used, whether it was a PCR test, a rapid test, an antigen test, or all these things, and now they have the home kits, a lot of these results did not interface at all or they were not built…there was not a corresponding LOINC code for it. There was not a SNOMED code for it. There were not these elements that were there fast enough. So, at the end of the day, here in Austin, when we were doing contact tracing, obviously, test results matter because hours and days mean exposure, and so, we ended up setting up two CLIA-certified labs just to process 5,000 lab results a day each just to get in front of the demand because the private labs got overwhelmed.

But, the problem was that we could not move fast enough in updating our systems to process the types of labs that we were starting to push through the system, so perhaps there could be an item on this crosswalk about future acceleration of lab results, and maybe there is a way under a public health declaration or whatever that there is something equivalent of a SNOMED or something to that effect that CCH IT systems can adopt and will be forced to adopt. Maybe there is a carrot for that.

And so, to the degree of it, I say this from in terms of a lab perspective, accelerating the results was only half the battle. The other half of the battle was associating it to the note, and half of the battle there was standards/lack of standards, and then sharing that information across the community. So, I would recommend that there is one more item on this crosswalk about accelerating the future, and that definitely comes down to speed of results and speed of that information to the clinician's hand.

Carolyn Petersen
Thanks, Aaron. I see we have two hands up, and we have two minutes to go to public comment, so I will ask Les to give us a brief comment.

Leslie Lenert
As was said in the chat box, I think we need to look specifically at how TEFCA can alleviate many of these problems, and to task ONC with looking at its existing framework, and then applying it to these problems.

Carolyn Petersen

Thanks, Les. And, in the last minute, Clem, one last, brief comment, please.

Clem McDonald

Home testing and these tests that are not done by labs are a big problem with COVID. We should focus on that, and I think we should be doing studies and not just deciding of our own insights. Similarly, with the registration data, that is a big, overarching problem. It is just not moving right. I think we should study it. We should get funding to analyze what is really going on because that should be solvable fairly easily, and it covers lots and lots of things. The third one is the fact that public health and healthcare operate very independently, almost with great joy to stay separate. I think they ought to be better merged. Public health has decided to make one style of dealing with the specimen and, generally, clinical healthcare made another, and those create problems. But anyway, we should focus on some general problem areas and get some study money to figure out what really is going on and how to do it better.

Carolyn Petersen

Thanks, Clem. And, with that, we will be moving to public comment.

Public Comment (01:17:01)

Michael Berry

All right. Thank you, everybody. I appreciate all the good discussion, and I would like to ask the operator to open up the line for public comments.

Operator

Yes, thank you. If you would like to make a comment, please press *1 on your telephone keypad. A confirmation tone will indicate your line is in the queue. You may press *2 if you would like to remove your line from the queue, and for participants using speaker equipment, it may be necessary to pick up the handset before pressing *. We will pause for just a brief moment. There are no comments at this time.

Michael Berry

Okay, and I just want to remind the public that if you are having any issues with making a public comment, remember to hit *1, as the operator mentioned, after you dial that number on the screen. Otherwise, you could always put something in the chat to us, and we will make sure that we get to your comment. And, I will turn it back over to Janet and Carolyn. Thank you.

Carolyn Petersen

So, I see a couple of hands up from our task force members. I will ask Steven Lane to go ahead with a very brief comment before we circle back and check on the public comment one more time.

Steven Lane

Thanks. Just very briefly, I just wanted to encourage the task force co-chairs to take the time to review the public chat. A lot has gone on there today, and I know that as a co-chair, sometimes it is not possible to monitor that during the course of a meeting, so, just to encourage you to take the time.

Carolyn Petersen

Thanks, Steven. That is an excellent point. We will definitely be taking a look at those logs, and they will be added to the transcript of the meetings that we hope will be appearing on the ONC website soon. Let's circle back and check once more for public comment, please.

Operator
There is no one in queue for comment.

Carolyn Petersen
Then, I think we will go back to Brett and Brenda for our next steps and what to expect in the next week.

Next Steps (01:19:37)

Brett Andriesen
Sure. Thank you, Carolyn, and thanks, everyone, for a great discussion today. So, we have our meeting again next week at the same time, and we will be finishing up some of the conversation we had today. It sounds like there will be some additional questions that we want to dig a little bit deeper into in terms of homework, and if we can move forward a couple more slides to the next steps one, we will get out links to SurveyMonkey, where all of the great information that we saw on the slides and some of the recommendations were pulled from. We will get those out by Friday, and just as a reminder, we will be sharing the responses to those questions with the task force members, as well as the public, as part of the material, so if you have not had a chance to go in and want to provide comments on some of the items that we are still discussing, please go ahead and do that, and then, we will get things turned around for the next meeting if you can get those to us by 10:00 a.m. Eastern on June 1st.

Carolyn Petersen
And, just to clarify for all the task force members, starting next week, we will be sending out some feedback to you because we are accumulating enough that we think it will be valuable for you as you review the recommendations to think about that, to have everything handy, and also as your prep for these meetings on Thursdays, so please be looking for that. And, if you have some other feedback you have not added to the spreadsheets yet, please do plan to update those in the next few days so that that is available for us.

Brett Andriesen
And, just another point that I would add there, Carolyn, we do have plans to get the recommendations crosswalk that we were looking at on the later part of the call today into a Google doc to allow task force members to provide comments using the Google doc's comment function and make iterations to those as we continue to discuss them and narrow this down.

Carolyn Petersen
Mike, did you have anything else to add? Are there other announcements or considerations, either for the task force or for the public?

Final Remarks (01:21:57)

Michael Berry
The only thing I will mention is that we are reconvening next Thursday at 10:30 Eastern time, and other than that, I do not have any other updates, so, thank you.

Carolyn Petersen

Any last, closing thoughts, Janet, or other business we need to wrap up?

Janet Hamilton

Thanks, Carolyn. I really appreciate everybody's robust discussion, and I think we all recognize that this is complex, and we are very grateful for all of your dedication and time and thought, so, thank you all.

Michael Berry

Okay. Thank you, everyone, for joining us today. We really appreciate it, and with that, we will adjourn today's meeting. We will see you next week. Thank you, have a great day.

Adjourn (01:22:56)