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

June 10, 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, everyone. And thank you for joining the public health data systems task force. I'm getting some feedback from someone. So, if you have your cell phone and computer on, one of them needs to be muted. Thank you. I'm Mike Berry with ONC and we really appreciate everyone's participation today. And I'm going to start with roll call. So, when I call your name, please indicate your presence. And let's 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
Present.

Michael Berry
Jim Daniel.

Jim Daniel
Good morning. I'm here.

Michael Berry
Steve Eichner.

Steve Eichner
This is Steve Eichner. Good morning.

Michael Berry
Good morning. Ngozi Ezike. Claudia Grossmann.

Claudia Grossmann
Here.

Michael Berry
Steve Hinrichs. Jim Jirjis. John Kansky.

John Kansky
I'm here.

Michael Berry
Bryant Thomas Karras.

Bryant Thomas Karras
Present.

Michael Berry
Steven Lane.

Steven Lane
Good morning.

Michael Berry
Nell Lapres.

Nell Lapres
Good morning.

Michael Berry
Leslie Lenert. Denise Love.

Denise Love
Here.

Michael Berry
Arien Malec.

Arien Malec
Good morning.

Michael Berry
Clem McDonald. Aaron Miri. Larry Mole.

Larry Mole
Good morning, everyone.

Michael Berry
Abby Sears. And Sheryl Turney.

Sheryl Turney
Good morning.

Michael Berry
Good morning, everyone. And thank you so much. And I'd now like to turn it over to Carolyn and Janet for their opening remarks.

Opening Remarks (00:01:55)

Carolyn Petersen
Good morning, everyone. It's great to see everyone back for another round of discussions and review of some of our questions and draft recommendations. We did present yesterday at the full HITAC meeting and had, I think, a very good response, certainly, some discussion around some of the things we've proposed and are considering. But I would say no major pushback or major concerns that are likely to derail the work that we're doing. The HITAC was very appreciative of the work that this group is doing. And I think Janet and I will have some further discussion about that this morning. Right now, I'll pass the mic to Janet.

Janet Hamilton
Great. Thank you so much. I, too, want to welcome everyone and thank you for your time this morning and also we're really looking forward to more robust discussion today. This group has been really thoughtful. And we really appreciate everybody's engagement. And so, I'm just really looking forward to that. And as Carolyn mentioned, we would like to spend a little bit of time as well just reflecting for any folks who were able to listen in yesterday on comments from the HITAC. And I think we are headed in a good direction but we also want to make sure that we are identifying any gaps or other spaces where we need further engagement. So, thank you all so much.

Carolyn Petersen
So, our agenda here is we will be going back to our crosswalk and looking at some draft recommendations. We will review feedback on some of the topics that we had sent out in the homework, the health equity and the ideal business flow survey questions and have some discussion and then, talk about our next steps,

what homework you can expect to see coming over the next week. We will have public comments and then, we will wrap up. Here is our roster, of course. I can start, I guess. Thinking about yesterday's meeting, we presented, of course, what we discussed so far in terms of guidelines, recommendations based on the feedback we've had. And we interpreted those and presented them to the group as draft recommendations that are under construction. We consider that we may change those based upon feedback that we get in the next couple of weeks on how they all come together as a group, which we will decide, again, probably in our last meeting.

Overall, the response was very positive. I was particularly pleased to see that the discussions we've had regarding the healthcare ecosystem as an ecosystem that involves the clinical side and the public health side as one ecosystem where data flows in both directions and individuals don't experience this as very separate entities. But it's just more of one thing that works together. That's something that HITAC is very much on board with. So, we are heading in the right direction in terms of the way that we think about what would go forward. As we've talked about a bit in this group, there is interest in talking about funding for public health. And while we indicated that we support increases in public health funding and would have some general recommendations about that, we would not be prescriptive in terms of trying to build a budget or give very specific guidance about what needs to be done. And I would say that the group acceptance of that was reasonable.

Certainly, there are a small number of individuals who would like to take it further. But I emphasized the need to stick with our areas of influence, which is health IT and public health data systems. And I would say that HITAC is on board with that. And I'll pass the mic to Janet for more specific discussion about specific points and recommendations.

Review Recommendations Under Consideration (Crosswalk) (00:06:54)

Janet Hamilton
Great. Thank you so much, Carolyn. Just a few other thoughts. First, I'll just expand on Carolyn's remarks related to looking at public health and healthcare as an ecosystem and public health as part of healthcare and that broad, overarching concept, which I think has been well articulated by several members of this group and, certainly, was supported by HITAC. I think the challenge that we have is, conceptually, it is easy to say that as a high level but how do we really strategically and more tactically start to operationalize that and create those types of structural shifts. And I know even for myself and my own language and discussion, it's hard to really construct the right framing to bring those things together in a truly meaningful way where we're really re-envisioning our approaches. And so, I would just offer if folks had thoughts on that, as well as when we go through our work together, how we can really try and bring that forward. I still think we're tending to make recommendations that are directed in one way versus another.

But it's a challenge for us to approach this and our language and recommendations in broader, holistic ways. So, that's maybe one thing I'll offer. And then, we do have a couple of slides for discussion today. And I will say we did also hear yesterday, and it will come up on these slides, even though our charge was, certainly, focused a lot on the response and things related to COVID and we as a group have been very thoughtful about that that there is a huge landscape of communicable and non-communicable diseases. And we really want to be appropriately thoughtful as we make recommendations from this group and maybe that we need additional work efforts in certain places but that we're not so focused just on the communicable, reportable disease aspects that we fail to incorporate the non-communicable pieces as

we're making recommendations and simply perpetuate the division that we currently see in some of our surveillance approaches.

So, I'll stop there and turn it back over to you, Carolyn.

Steven Lane
Janet, can I offer a response to what you said?

Janet Hamilton
Sure. Carolyn usually does such a great job of managing comments. But yeah, absolutely.

Carolyn Petersen
What I would just say is please, Steven, if we can be mindful of the time and not launch into a discussion that takes today's meeting back to yesterday and prevents us from going forward. That's all.

Steven Lane
No. This is a new idea. Janet, what you were saying was how do we make that shift to the idea of public health and clinical being a collaborative ecosystem of care or individuals in the community. And I was thinking, clearly, so much interoperability started as provider/provider. And then, we expanded into provider/patient. And we've expanded into provider/payer. And in each case, there was a clear kind of business driver, if you will, to make that happen and a whole community that's grown up to support those new types and means of exchange. And I think we don't have the same financial business driver in public health or not an obvious one where people see the benefits to the whole community and society and they're willing to just jump right in and pay for it. But yet, we have this opportunity of all of this new funding. And I just wanted to say this is a new thing. And you're right. We need to speak to it using our language. We need to do everything that we can.

We need to do the work that we're doing here to drive that forward. But I think we all believe in that future state of an integrated ecosystem of care on the public health and clinical side. I just wanted to make that observation.

Janet Hamilton
Very nicely articulated. Thank you.

Carolyn Petersen
And that also points out maybe it's not a need as yet but, certainly, it is a part of the task of thinking about what is out of scope for that broadening because to bring public health and the clinical side together, there is a point where you're moving more towards a system that could be framed as a single payer system or that would be a very challenging hybrid if there was both the private commercial side as well as the governmentally managed programs. And I think that kind of visioning is definitely outside of the scope of this group. So, what we do, we need to frame interactions but also avoid taking it so far that it becomes problematic in terms of defining the work of the next six to twelve and eighteen months. So, with that, are we ready to step into the next section, Janet?

Janet Hamilton

Yeah. I think so. Let's go ahead.

Carolyn Petersen
Could we advance the slides please? So, I will do a quick review of our charge just as a matter of helping folks who are on the phone and don't have the Adobe in front of them. We are 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. We have two tasks. First to identify and prioritize policy and technical gaps associated with the effectiveness, interoperability, and connectivity of information systems that are relevant to public health, including the focus on surveillance systems, infrastructure improvements, health equity, clinical engagement, research and innovation, and educating and empowering individuals. And secondly, we need to identify the characteristics of an optimal future state for information systems relevant to public health and their use. Next slide please. We also presented for HITAC yesterday and present here this updated task force scope.

And this is the reaffirmation that we are focusing on bidirectional data exchange between public health data systems and clinical data sources. We're focusing on challenges, gaps, and ideal future state for data sharing between public health and the clinical data sources, which includes things like EHR's, laboratory systems, vaccine management software, and other relevant data sources. Topics that are previously in scope that will now be recommended for future HITAC discussions include research and innovation, social services data, and in depth analyses of specific public health data systems. Finally, recommendations and discussion surrounding health equity and patient engagement will be addressed in the topics as we come to them rather than being managed as unique topics for meetings and categories for recommendations. And I think we've all seen that. Next slide please. So, now we get to the part of the program where we talk about some draft recommendations.

And I think this is where our partners will bring up the crosswalk. Great. And that's coming up on the screen now. If there is a way to make it a little bigger that would be helpful. So, we have at the top of this page the recommendations. Are you still moving it around? We'll be set here technically in a moment. Thank you. So, the first recommendation here is syndromic surveillance as the topic. And we have a gap, which is there is an availability of rich data that is not tapped into to support syndromic surveillance.

Janet Hamilton
Carolyn, this is Janet. And I think we need to move down. This is where we started the last time.

Carolyn Petersen
Okay. I wondered if we were going to go back through this again but that's what came up.

Janet Hamilton
I'm just trying to think about getting through some new ones.

Carolyn Petersen
Yeah.

Janet Hamilton
Super. Sorry.

Carolyn Petersen
No, that's okay. Shall I start with patient privacy and digital access and work from there?

Janet Hamilton
Yeah. That looks good. Great.

Carolyn Petersen
So, our topic here is patient privacy, digital access, and social justice factors affecting key surveillance use cases. The gaps are three. First, a lack of alignment in jurisdiction versus state versus federal privacy and security laws and a lack of clarity within HIPAA on data sharing for public health purposes like the minimum necessary. And that leads to differing interpretations from each state and local jurisdiction. Also, there is a lack of interoperability adaption incentives for public health data sharing across states and a lack of funding overall. And third, there is a lack of federal guidance and restrictive state laws on data sharing from public health to external intermediate entities. And that would be things like public health requests for PHI, HIE's, and research. There are no opportunities identified at this time. And if we could move the slide a bit to the left, I will review the feedback we've received so far.

So, the feedback that we can use for recommendations includes ONC and CDC should work with OCR to develop and release best practices and guidance for meeting the HIPAA minimum necessary standard for reporting to public health authorities. Such guidance should be aligned with TEFCA to allow national networks and HIE's to serve as public health intermediaries. Additional feedback was added that, ideally, any FHIR based data specific request submitted by public health to a provider organization should be declared to de facto meet the minimum necessary requirement in HIPAA for non-treatment related public health queries where public health does not have the ability to send FHIR queries and rather must utilize queries for available CDA documents like CCD, EICR. There should be a simple standardized process for the OCR or the public health agency to declare that the request satisfies the minimum necessary requirement at least in the context of the declared public health emergency.

With that, I will start watching for hands and identifying individuals to respond. Let's start with Danielle Brooks.

Danielle Brooks
Hi. Thank you and good morning. I think one of the things that I would like to bring awareness to, and I'm not sure how it should best be documented, but the alignment of other data sharing capacities. Recent privacy updates to HIPAA and data sharing doesn't really address the use of this data as discriminatory. And so, as we look for alignment between ONC and CDC and OCR, I think there needs to be enhanced scrutiny on making sure that the data is protected and cannot be used by other third parties. One of our feedback from the group is highly representative of refugee and immigrant community is that fear that that type of data would go third party to other entities that are looped into the health system like ICE and those departments. And so, that data could be used as discriminatory. So, I think we do need to make sure that there is a balance between the two understanding that public health emergencies do have a different standard.

In order to get people to better share that data, we just have to make sure that data does not leave its intended use and can be used for discriminatory purposes.

Carolyn Petersen
Thank you, Danielle. And another consideration in forming the recommendation that addresses this might also be a reference to other secondary data uses by other governmental agencies or their partners and partnerships.

Danielle Brooks
Correct.

Janet Hamilton
And this is Janet. I'll just add to it that it's probably worthwhile when we think about the recommendation to ensure that the right level of public health has access to certain types of information. So, state and local health departments will need certain types of data. But that's just not needed at the federal level. So, identifiable information absolutely state and local level so that they can do case investigations and follow up but the federal government does not. And that should continue to be stripped out and removed.

Carolyn Petersen
Let's go to Arien. And, again, if anyone on the task force has a comment, please raise a hand and I can identify you in order.

Arien Malec
I've already submitted comments into this box. But as a pretty basic comment, I spent a fair amount of time early in COVID times clarifying the term surveillance. And I wonder whether the public health community would be better served by picking a term, and I know how deeply embedded it is in the public health community, that does not so easily lend itself to confusion that the intent is to spy or collect information about citizens that's used in nefarious purposes. So, that's one meta comment. And the other is to go along with the HIPAA minimum necessary for public health, I do think there need to be a corresponding framework. And this may already exist and just needs to be better publicized. A corresponding national framework for how public health data are used and what the individual privacy protections are that are associated. And I know the public health community has been incredibly sensitive to privacy protection and minimization of use.

But it would be useful if there was a national framework for privacy protection and use of data to get away from some of the concerns. But even some states like California have raised relative to federal participation in data sharing. Thank you.

Carolyn Petersen
Thanks, Arien. Let's go to Steven Lane.

Steven Lane
I think one thing that **[inaudible] [00:24:53]** is always reminding me of is that the policy framework that surrounds required disease reporting versus case investigation is different. And the role of the minimum necessary limitation on public health exchanges is only applicable to part of that. And as we've discussed,

and as I discussed yesterday at HITAC, I think that we need to be looking at yet a third rail here, which is the ongoing care of patients and looking to support collaboration. So, I think there is reporting, there is investigation, and there is care. And we need to think about how this minimum necessary requirement should or perhaps should not apply in each of those situations. The minimum necessary requirement, to my understanding of HIPAA, has to do with non-treatment related exchanges with public health. So, it probably applies primarily in the case investigation area, not in the care area.

And, again, I think the rules around reporting are pretty prescriptive in terms of what data should be reported. So, I just think we have to think about these in buckets.

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

Bryant Thomas Karras
Good morning. I, actually, now have two comments. One on the last point, I agree that there is a continuity or there is a distinction between initial case report and a deeper further investigation. One thing that the COVID-19 experience has led us to is an understanding of public health's role in the treatment paradigm, not just as a public health partner but as an actual critical member of the treatment and active care of individuals. For a long period of time, our public health laboratory was the only location that could assist in the diagnosis. So, we needed to change our approach of us collecting data from others and then, keeping it protected only for public health use to sharing that with our clinical partners so that they could best take care of people when they re-emerged in an Emergency Room with a decompensation, for example. We might be the only people in the healthcare ecosystem that knew the test result. So, I think it's really important that we rethink some of our previous assumptions on the role of public health in that exchange.

Going back to two comments ago, I couldn't agree more with the concern about federal partners not needing to have all of the identifiable information on patients for CDC to do national roll ups, for example. And I'm not sure if this is in the scope of this task force approach but now that borders are reopening, there is an increased focus on do not board lists and public health look out lists to be shared with TSA and customs and border protection, respectively. And in those situations, it is identifiable information in that there may be some of the very institutions that some community members are concerned about sharing with. We need to try to be cognizant of that.

Carolyn Petersen
Thanks, Bryant. Let's go to Denise Love.

Denise Love
I'm going to go back to minimum necessary because I've struggled with this for decades. And it does become applied very differently depending on who is applying it. But public health really needs the detailed granular data coming in. I just wanted to emphasize that. I'm sure we all agree. But maybe better guidance and standardization or framework for how the data are suppressed or aggregated so that we're finding that balance between not masking the pattern of some of the small populations but we are sensitive in how that data are reported and reused in the public domain. I just wanted to draw a distinction because minimum necessary going in is a problem for public health. But how we treat the data going out is really important.

And that's where some of the funding for public health really could be used for data scientists at the local level to work to do a better job of aggregating, suppressing, but not masking. A big ask. Thank you.

Carolyn Petersen

Thanks, Denise. Do we have other comments from task force members? Please rise your hand in Adobe. And also, if there are any task force members who are just on the phone and would like to speak, please let us know. Do you have any other comments about these recommendations or this piece, Janet?

Janet Hamilton

No. I just think emphasizing Denise's point is really critical. For public health surveillance, and I realize maybe that term can be used in ways that makes people uncomfortable but that function is exempt from HIPAA and detailed information is needed. But how the information then is shared, I think there can be additional guidance on that. And I'll still say that there is confusion about the need for that detailed data for public health surveillance purposes. And I think additional guidance could be developed there as well so that it is more explicit to more providers around the need for that detail to come in.

Carolyn Petersen

And that sounds like something that this group is very, very well placed to provide guidance on to put some recommendations in that get to that. Certainly, we know on the consumer side that understanding about where HIPAA applies and where it doesn't is always a challenge. And thinking through the downstream effects to what that, actually, means for a person in any given situation with any particular kind of health information is confusing and challenging to sort through.

Steve Eichner

Janet, this is Steve Eichner. I think one of the other places where we need to balance as well is ensuring that public health is getting the data that it wants and needs in a findable way so that if we're requesting certain information about a patient for disease investigation, we're not getting the patient's full CDA record at discharge with 152 pages of data when we're looking for a more limited data set and then, have to review all 152 pages if that's not what we're looking for. Does that make sense?

Janet Hamilton

Yeah, absolutely.

Steve Eichner

Because the balance two ways, we've been asked for public health by providers to provide real targeted information so that they're not looking for small pieces of data either from public health or from other providers looking to identify the critical components for their patient. We're in the same kind of position that focusing the results becomes important. So, there is that balance component about the provider's ability to supply the information that we're looking for, which we're doing, in part, with the standardized messaging for a lot of reporting and looking at FHIR extracts that can support that. So, I think there is a balance point that we've got to figure out how to reach it without creating unnecessary administrative burden on the providers as well. I'm not sure how to finesse that point.

Carolyn Petersen

Thanks, Steve. That is definitely another comment we will capture and use in framing our recommendations. We're going to move on to the next topic now. We've rolled down the crosswalk if you're in Adobe. And this topic is policy, licensing, and legal factors affecting key surveillance use cases. We have two gaps here. First, a lack of alignment of HIPAA with current use cases, population based data sharing, data sharing with non-HIPAA covered entities and such. And also, FQHC's and individual providers lack resources to establish connections with public health. We don't have an opportunity identified yet. And could you slide the slide to the left a bit? The commentary we have so far is that ONC and CDC should work with OCR to develop a national framework for the collection and meaningful use of standardized SDOH data starting with those elements included in USCDI entitled Enforcement Incentives and Linkage Strategies to Cross Fertilize Key Data Sets and Reduce Collection Burdens is also a concern.

And I see Bryant's hand is up. Please go ahead, Bryant.

Bryant Thomas Karras

I'm just trying to draw on experience from past that maybe was head of its time. There was an initiative that CDC and APHL, I believe, funded more than seven or eight years ago to provide technical assistance to connect electronic laboratory reporting to public health. And resources were put into consultants who could be deployed out to hospitals in order to make connections to public health. And it was one of those situations where people didn't know what they needed at that point in time. And there were very few institutions that took them up on the technical assistance. But I'm wondering now with the heightened visibility if a similar approach of providing technical assistance to those FQHC's that were struggling with not having the resources to make these connections and investment in a nationwide capacity of consultants to be deployed to help fill that gap would be of value.

Carolyn Petersen

Thanks, Bryant. Do we have other task force members who would like to comment on this topic, please raise your hand in Adobe. Steven Lane, please go ahead.

Steven Lane

Yeah. I think one of the problems is, and I was just looking at the document that Heidi referenced in the chat, is that the current structures are permissive. That is to say they allow providers to share data with public health but they are not prescriptive or they don't force them to share them. And I think one of our challenges is shifting that paradigm because I talk to provider organizations. And they're like, "Yeah, we know we could but we're worried about the privacy issues. And our patients have concerns so, therefore, we're just not going to do it." And I think that we need to figure out how to align this with the information blocking provisions and the evolving TEFCA so that, as we were saying at the beginning that sharing with public health is really akin to sharing with other providers. It's something that you are expected to do, you're required to do as opposed to something that you're allowed to do because that's where everyone gets hung up waiting for OCR to provide verification.

Carolyn Petersen

Thanks, Steve. Bryant?

Bryant Thomas Karras

So, I was just going to ask a question to Steve. Shouldn't it be a state declaration of what they want reported to them rather than the feds? So, I think the HIPAA and the federal rules are permission. And then, it's up to the states to declare what is required to be reported to them.

Steven Lane
The states of the jurisdictions. We saw that in Chicago.

Bryant Thomas Karras
It's a formal rule.

Steven Lane
So, what we've seen in the context of COVID is that that is not scalable. It doesn't work. Only a few jurisdictions have, actually, pulled that off. And it's incredibly burdensome for providers because it's just different everywhere.

Carolyn Petersen
Seeing no other hands in the cue for comments by our task force members, we will move to the next topic. This one will probably bring about some discussion. This is patient matching between public health and clinical systems. I think there are no gaps and opportunities there. But I think probably for most folks in the room, those gaps and opportunities are pretty apparent and pretty well recognized. The commentary that we have here to use for recommendations so far is a minimum set of data elements should be defined to complete patient matching across public health and clinical systems to include demographic information. The complete collection and submission of this information should be incentivized. So, task force members, please put your hands up in Adobe and let's start with Denise Love.

Denise Love
Yes. This is a topic near and dear to me. And I've been interviewing states on another project. There is a lot of linkage going on in states right now and quite impressive infrastructures. So, I would just add to a recommendation for each state to do an inventory of both their HIE and their public health and their Human Services Department and collaborate with already some pretty extensive linkage that's going on with data sets across the whole spectrum, including social service. There are states that are doing this. And public health should be at the table if they are not. And there are linkage infrastructures in place that public health should take advantage of if they have not already. That's just my two cents.

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

John Kansky
I'm going to add my two cents to what Denise just said and make four. She was reading my mind. It's very desirable, especially on federal task forces, to want to devise something that just works everywhere across 50 states and 6 territories. There are places, for example, I think Colorado is one example, where the HIE's master person index is being leveraged across state agencies even beyond public health. And, certainly, in Indiana is an example of a place where the HIE can serve in a global matching role between the clinical and public health setting. So, just exactly what Denise said. She said it better than I did. Thank you.

Carolyn Petersen

Thanks, John. If we have other comments from other task force members, please raise your hand.

Janet Hamilton

This is Janet. Maybe while we're waiting for others to raise their hands, I think maybe the intent of this isn't to imply that there isn't good matching that's occurring but that when information is being shared and provided that there is at least a minimum amount of information that moves along with the person so that the matching can occur effectively and with the right level of assurance that a patient is being appropriately matched. And I think they are great spaces where there is matching that's already happening but how do we think through the spaces where we can't make matches and ensure that we're also enabling that to happen in a way that is productive and useful.

Carolyn Petersen

Let's go to Denise Love.

Denise Love

Janet, I agree. And I think this gets back at the ecosystem in the states to be sure that they're harmonizing those demographic data elements across the data sets that those robust patient identifiers are there on the intake. And it's very different from how they're used or re-released. But some of the states with their matching have developed encryption and other methodologies to visage the concerns. But that is an ecosystem question the public health needs to avail itself in. And some data sets don't get all of the requisite demographic information so those linkages are not as robust. But, again, I do think linking in or connecting into what's happening at the state level is important for every public health data set.

Carolyn Petersen

Thanks, Denise. Let's go to Arien Malec.

Arien Malec

Just as a friendly amendment for the wording here, I think the intent, as Janet expressed it, would be better served by saying minimum set of identifying demographic and contact related data elements should be defined to exchange to enable patient matching across public health and clinical systems.

Denise Love

And do we need minimum?

Arien Malec

Well, we don't want to cross reference minimum necessary. There is at least some set of core information that is routinely collected and should be transmitted to enable identification so maybe core could be used instead of minimum.

Denise Love

Robust, core, detailed and standardized because we want it to be clean across all sharing elements. Right. The problem with minimum, sometimes the data submitters interpret what they want as minimum and not what is really needed.

Danielle Brooks

Yeah. So, maybe core standard might be the best way of describing it.

Carolyn Petersen

Thanks. It sounds like this is something that we will revisit when we have a draft recommendation around this to think about any phrasing to include or exclude some things or be more specific. Let's go to Danielle Brooks.

Danielle Brooks

One of the things I think is also important, and I'm not quite sure how we articulate this, but I'm having a little bit of difficulty with public health. So, one of the things that we're experiencing now with vaccination data is that the mass clinical sites, they are not reporting throughout a standard. And these are sites that are set up at gyms and parking lots, etc. And so, I think that there needs to be recognition of when we do contract with these private entities or entities that are non-clinically based for this outreach and work, either it be testing, surveillance, or distributing vaccination and the other treatment. There needs to be some sort of repository connection to these sites that are not standard clinical sites.

Carolyn Petersen

Thanks, Danielle. Seeing no more hands on this topic and realizing that we're probably going to need to revisit it when we've got some draft recommendations around it, I think I'm going to suggest that we move to look at the feedback from last week's homework if we set aside our crosswalk for now. And I think, Janet, you were going to lead this discussion or do you want me to call on people and facilitate that part?

Janet Hamilton

Well, Carolyn, you're such an expert so that would be good. I can introduce the topic and then, if you want to manage the comments, that's wonderful. So, this was related to folks' homework and it's about health equity. And I think, certainly, we have been addressing health equity in many of our discussions. But we also really wanted to focus on it a little bit more explicitly. So, these questions were part of the homework and we'd love to have some discussion here as well. So, the framing of these questions then, what is the root cause behind why race, ethnicity, disability, LGBTQ, primary language, or other equity data are not captured and reported to public health frequently. And also, to really challenge people to think about what is the ideal future state for better capturing race and ethnicity and other health equity data when lab results or suspected cases are reported to the Public Health Department.

The other question on this topic that was also part of the homework is what can be done to move us towards this ideal future state in terms of these potential areas or recommendations that could focus on standards, including content and transport. What must the public health receiver system to? What does the EHR need to do? Is there a role for certified EHR's in the certification process? Any types of centralized infrastructure? Incentives for providers to implement the collection of this information or on the side of public health. And then, if there needs to be any technology infrastructure to support the collection of this information in non-traditional settings as well. So, if someone were going to be potentially collecting something in a home situation, I think we just heard about drive through schools, etc., maybe we need to ensure that there is some level of technology infrastructure that would allow individuals to provide some of the information. So, those were the questions and we would love to get some comments and feedback on them.

Carolyn Petersen

Task force members, go ahead and raise your hands please. Let's start with Steve Eichner.

Steve Eichner

Good morning. I think part of the issue looking at data or disabilities is that we really don't have any national standards for describing disabilities in terms of the functions of activities of daily living like I'm a wheelchair user or I can't walk more than 300 feet or I can't raise my arms on down the line. And because we don't have those standards, we don't really have a method of collecting the data. That being said, I think we, actually, are inadvertently working towards some standards in that space as we look towards information that's being collected by public health or by public safety for things like evacuation services or disaster assistance services where there is data collection going on with respect to what services might be needed by individuals who need help with evacuation. So, we've kind of got a leg up. We may not realize it but that's something that we can take advantage of and put that together.

But I do think it's important in that space to focus on the impact of the disability, not the condition that's causing the disability in terms of what's the disease because if you're just looking at the root disease, you're not really going to end up with comparative or useful data to understand how that impacts people's lives and how public health can change its services to better meet that population. I also think we've got some educational opportunities to provide better guidance to providers in asking questions as to whether we're providing a list of responses for people to select from or whether we're looking at a more engaged approach to get more detailed information. I think communicating why the information may be relevant to the patient is really important and what are the impacts on the patient. I know there is concern about perceived prejudice or prejudice, depending upon the answer to the question. So, that's something that we need to overcome on the communications end of it. Thanks.

Carolyn Petersen

Thanks, Steve. Let's go to Denise.

Denise Love

I think some of the root causes include design of our systems and I'll get to that in a minute. And it's cultural. It's even sensitive for the entity to collect it. Some entities feel it's inappropriate to ask race, ethnicity, and some of these other sensitive data elements. So, we've got a cultural issue and a systems issue. And I'm thinking of the systems issue as a macro design issue. What are the key sources where we absolutely have to have these sociodemographic data elements? And how can we design that in? For instance, lab systems were designed in a different time and era where these data weren't necessary for the function of the lab system. And the cost to retrofit those systems are, I think, quite costly. Where are the key sources where we can capture this information like enrollments? We need to do a better job of capturing them at points in the system that then could fertilize other systems that maybe aren't designed to capture these data elements at every point of care and contact. I don't think that's realistic for every contact with the patient to capture a suite of sociodemographic data elements and then, share them through the system.

So, if we can think about design.

Carolyn Petersen

Thanks, Denise. Let's go to Danielle Brooks.

Danielle Brooks

I would, actually, agree with the past two commenters with a slight modification. Two things. I agree with the chat box. LGBTQ should be changed to SOGI data, which emphasizes sexual orientation and gender identity across the spectrum. That way, that data element can be more robust and complete because in the LGBTQ, that's still keeping in specific categorization. Also, the concept of primary language should be hyphenated or slash with the preferred language because there is a difference between a primary language and then, what you prefer to have your medical information put in. And I think when we talk about the root cause, I would agree there are design flaws. The way the current captured demographic data and other social data is based on a standardized and it's a systemic standardization through a very specific lens. Specifically, the way the data is collected now on the back end, you have main racial categories. And the interesting thing about that is when you break down the ethnicity in the racial categories, it's, typically, black, Asian, AAIP categories, Middle Eastern, other and then, white.

And when you go into ethnicity, white does not have ethnicity markers, typically, in most systems. It's just white across the spectrum. So, we're not really getting detailed information about ethnicity. So, I think when we think about this design, we really do need to think about how we're collecting it and for what purpose. The typical boxes that OMB has are not a satisfactory way of collecting demographic data. In order to, actually, get it to a proper way that is helpful for surveillance and to impact this public health threat, we need to get to more granular data. And so, I would suggest there is, actually, a concentration on ethnicity over race because then, those categories can be rolled up. About the source data, I do agree that it's not realistic that you're going to get data across the spectrum. But the flaw with enrollment data is that it's, typically, unreliable. And the reason why is because there are strict categorizations that most people do not necessarily fit in or really feel like they're a part of.

So, I do think that there needs to be significant work on the way that we capture this across the spectrum and how it is used. And also, making sure that this information, again, is shielded from discriminatory potential. And the last piece I'll say is that there is a significant education campaign that needs to be run both on the consumer angle and the health systems angle. In my practice, I find people that are in the health system are more uncomfortable asking the question than people are providing the answer. And so, this just needs to become a standardized component if we are to truly understand health equity because we do need to be able to measure our populations and understand where those disparities exist. Thank you.

Carolyn Petersen

Thanks, Danielle. Bryant.

Bryant Thomas Karras

So, many of the comments have already been made. **(Audio interference)**. I want to compliment and commend some of the exciting work happening **(audio interference)** and CDC efforts to advance sexual orientation and gender identify as well as race and ethnicity categories. The task force should recommend continued investment and coordination of those efforts and our recommendation that OMB create more granular capabilities so that those stakeholders that want to take advantage of them can but that there is a way to grow them up to jurisdictions or national systems that haven't been authorized for having **(audio interference)**. The last comment I'll make is one that they create a story of experience in partnering with

the American Indian **(audio interference)**. We've had reasonably frustrating experiences that every year, we try to make updates to our systems **(audio interference)**.

Carolyn Petersen
Bryant, we're having some trouble hearing you come over the phone. Are you able to get closer to your mic or move position?

Bryant Thomas Karras
Is this better?

Carolyn Petersen
That's a little better. Yes, please.

Bryant Thomas Karras
(Audio interference). Working with the American Indian and **(audio interference)** population, they've made corrections in our database each year to make sure that we're identifying and then, the following year, all of those corrections have been written over by systems depopulating and **(audio interference)** the same databases. So, we need to come up with better ways to make these identities stick across our **(audio interference)** systems. Thank you.

Carolyn Petersen
Thanks, Bryant. We did have some static and some difficulty hearing some of your comments. So, I would ask if you could post URL's to the work or the organizations you were referring to and then, we can be sure we get that captured.

Bryant Thomas Karras
(Audio interference).

Carolyn Petersen
Thank you. Denise Chrysler.

Denise Chrysler
Sure. I wanted to add to some of the things that Danielle said. And if Bryant said this, I apologize. I had a hard time knowing what was all included. I really support the importance of subgroups. Within the broad federal categories, there is so much that is diverse culturally and history and language that it's important to public health in designing interventions and assessing how well things work. But at the same time, remembering as we create new and improved to be able to roll up to the past, I think that's the term, because we still need to roll up subgroups or changes in how we describe the data elements to what we've used in the past such as the federal broad categories in race in ethnicity so we can compare to the past and so we can be able to compare to one another because states will be on a very different trajectory as they incorporate the new and improved.

Carolyn Petersen
Thank you. Are there any other comments from task force members? Please raise your hand and I'll recognize you. Do you have any comments you want to probe or any further work to do on this set, Janet?

Janet Hamilton

I think this has been great discussion. I think many of the comments were at that highest level. So, I don't know if there are any other folks that would like to make comments more on the ideal future state or any other suggestions, which I realize that's at a very high level but might be at a more granular level. And then, one thing that we didn't really touch upon at all was that last piece around any types of technology infrastructure to support how we're doing work when we have really non-traditional settings and really to engage individuals in provision of some of that information as well as potentially incentivize certain companies or other types of activities to, actually, be able to collect some of that data from individuals as well. So, I'm wondering if folks have any additional pieces on those aspects.

Carolyn Petersen

Are there any task force members on the phone who have comments or would like to weigh in? Let's go to Danielle Brooks.

Danielle Brooks

Just briefly, just capturing the question of how to get that data. I think there just needs, again, to be a real care with asking the information. Individuals are fine with providing it if they know where the data is being housed or used. So, again, as we look at these opportunities to improve health equity in the ideal business case that education and trust building is essential because, again, there is a lot of historical rationale and current rationale for why people may not want to divulge that information. So, as we look at those opportunities and really constructing those standard questions and rationale of why and really enhancing those privacy concerns go hand in hand. Thanks.

Carolyn Petersen

And I see Denise Love has her hand up. Go ahead, please.

Denise Love

I'm going to sort of channel Dr. Michael Stoto a little bit and I hope he doesn't mind. But he talks about that we need a framework. We talk about the individual data collection and release and use but kind of a holistic framework because, right now, we have variation and reported data. We have case surveillance data with problems. We need standardized case definitions. But we need a system to put it all together to do a better job of identifying patterns and analyzing. And it's complex but it puts together, not only the standardized methods but putting together different data sets, surveys, and syndromic surveillance to look at population based data in a framework that uses the sociodemographic data better and in a more standardized way. And I would refer to some of his work proposing various frameworks for capturing and using this information more holistically. That gets buy in from the people supplying it, more utility to the data that is captured and used, and more uniformity in how it's used.

So, I hope he doesn't mind that I channeled his discussions.

Carolyn Petersen

Thanks. And we have one last comment from Steve Eichner and then, we'll go to the next set of questions.

Steve Eichner

Thank you. I think it's important that we figure out how to segment the data for things like disabilities and racial components so it's not shared back inappropriately so we're maintaining patient privacy. And I think we can figure out a way of using technology to share that with patients and individuals becomes critical so that we're not looking at too close of a data merge and looking at how that data is, actually, going to be used for what purposes. And being absolutely clear with submitters about how we manage that becomes critical. Thanks.

Carolyn Petersen
Thanks, Steve. Do you want to go ahead with this group, Janet?

Janet Hamilton
Thanks so much. So, we're going to go ahead and move on. And I think some of the feedback that we have gotten is to also push ourselves to think a little bit more about ideal. And so, I know we have talked a bit about lab and lab reporting amongst this group but we haven't necessarily flushed out a little bit more what we think is the ideal state. So, we did ask people to think a little bit about this in the homework and wanted to bring that up here for discussion and see what other thoughts people might have to say. But given what we've learned from COVID-19 as well as other recent public health responses like Zika or Ebola to describe the ideal business case for laboratory reporting from the perspective of the health departments, the provider, the payer, and other stakeholders. And what should the ideal business flow be for that data for all stakeholders? And how do we, actually, get there in terms of standards, content, and transport? Again, similar types of questions as what we saw before.

Any comments on what the EHR might need to do, any thoughts around role of certification for EHR's, centralized infrastructure that could help support moving data or that process and, again, role of non-traditional testing locations. And if we can talk about what the ideal is then, how do we get there? Are there additional incentives that we might need to get to that ideal state?

Carolyn Petersen
Let's start with Steven Lane.

Steven Lane
My initial thought is that we missed calling out patients and communities as stakeholders and that we talked about some of the challenges around privacy and around individuals not wanting their information collected or shared. And I think that we should think about patients, individuals as stakeholders independently and think about what is the role of public service announcements and public education, of an effort to help people understand that having this information collected and reported benefits not only them but their families and communities.

Carolyn Petersen
Thanks, Steven. I think you know from our various task force work on the HITAC, that's, certainly, a point that I would echo and fully support. Patients as actors in the public health system that we're talking about is maybe not as obvious. But it, certainly, is a function that we need to capture and keep in mind as we look at the recommendations and finalize those. So, thank you for that. Are there other task force members who have comments to share? Please raise your hand in Adobe. Are there any task force members who are just on the phone who would like to comment? Bryant, I see your hand up. Please go ahead.

Bryant Thomas Karras

Just briefly, I think that EHR certification is focused on minimum. And I think that to get to that ideal, we need to raise the bar again and make sure that the capacity to do the deeper requirements that meet public health's needs rather that the minimum is set as a net standard **(audio interference)**.

Carolyn Petersen

Thanks, Bryant. I think we're having some audio issues again.

Bryant Thomas Karras

(Audio interference).

Carolyn Petersen

Okay. We can connect by email also after the meeting if we continue to have trouble. I know sometimes the audio can be a problem. With that, I think we will go to our public comment. And we often have a bit of time after that. So, I think we'll circle back and see if there are any additional comments about these questions from our task force members. Sometimes, it takes a minute to gather your thoughts. After we do public comment, we'll touch base on that again briefly.

Public Comment (01:15:18)

Michael Berry

Thanks, Carolyn. Operator, can we please open up the line for public comments?

Operator

If you would like to make a public 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 the handset before pressing the star keys. We will pause for a brief moment to poll for comments.

Michael Berry

And while we're waiting, I'll just mention that our next public health data systems task force will be next Thursday on June 17. Operator, do we have any public comments?

Operator

There are no comments at this time.

Michael Berry

Thank you. Carolyn.

Carolyn Petersen

Could we bring up that last set of questions please that was on the previous slide? We're just circling back in case any of our task force members have additional thoughts to share on the health equity and ideal business flow future state. This is a really important area and I know sometimes, in the midst of a discussion, things don't always occur immediately. But we really do want to make sure that we get an appropriate emphasis on this area in our recommendations. So, I think I'll start with Steven Lane.

Steven Lane

I really wanted to ask a process question. We, obviously, answered these questions, or some of us did anyway, in the homework. And I noticed that those answers were not brought forward and displayed and discussed specifically. Are you planning on capturing those results and the results of our discussion and putting them into a spreadsheet for our review and commentary?

Brett Andriesen

That's the plan going forward for that, Steven. Those will be in the Google Doc.

Carolyn Petersen

Thanks. Let's go to Steve Eichner.

Steve Eichner

Thank you. I think something we really need to look at is the use of health information exchanges and other data resources to augment the information we have about race, ethnicity, disabilities, and other sources. One advantage using HIE's to route test results or test orders is that HIE's are **[inaudible] [01:17:57]** to store a lot of information about individuals. By routing a laboratory order through the HIE, the HIE could, potentially, extract the demographic information and forward only that information necessary to process a sample to the laboratory and then, on return repopulate the demographic and other **[inaudible] [01:18:22]** entry fields on its way to public health.

Another advantage in leveraging this kind of environment is that the test results could also be directed to the patient's regular care team in a situation where a patient has been given a test outside of the normal care environment such as through drive by COVID-19 testing, for example, where the test might not have been ordered by the patient's regular PCP or regular hospital or even someone they've never seen previously. And that would really help facilitate care and coordination and really is another way of leveraging those resources. Thank you.

Carolyn Petersen

Thanks, Steve. We do have another couple of minutes. So, again, if our task force members have any further input or discussion for these questions, please raise your hand. Denise Love.

Denise Love

I'm a little chatty today. I just wanted to put out there that the National Committee on Vital and Health Statistics Standards Subcommittee is working on some common issues as well. And the intent is to collaborate and coordinate our findings with this and ONC's work. Some of the convergence issues are harmonization of key data elements and common framework. So, I know there will be a listening session with industry and other stakeholders in August. But I just wanted to be sure I put it out there that we cross communicate some of our findings with the important work being done here so that we can come to some common decisions and framework and leverage those where they're needed. Thank you.

Carolyn Petersen

Thanks, Denise. That's a great point and, certainly, may be information that helps us to develop the recommendations or things that we want to reference in citations that support the recommendations we

make. If you have URL's that you can post in the public chat either this week or next or if you want to send that to Mike Berry or Janet and I, we can work to get that distributed to the task force.

Denise Love

Right. And I think you may be speaking. We'll let you know. I think the federal register notice will go out in the next few weeks and I'll be sure to circulate those with everybody.

Carolyn Petersen

That would be great. Thank you so much. I see Bryant has raised his hand and we'll take the comment as well.

Bryant Thomas Karras

So, I just made a couple of comments in the text that I think we may want to make a recommendation that certification processes takes a deeper dive into, especially the public health measures, which in the early certification process, not only bare minimum often times only looked at superficial, structural compliance and didn't get into actual data elements that are required by public health. And it definitely didn't get into checking that vocabularies and LOINK and SNOMED codes were included and handled appropriately, I think, often times because that can't be tested until after deployment. So, I think that to prevent the burden falling on public health to help fix broken messages, we really need to have the partnership between the EHR/EMR members and their customers needs to take it up a step in terms of responsibility so that they can help public health to do our job. Thank you.

Carolyn Petersen

Thanks, Bryant. It looks like we have two minutes left. So, I will conclude my comments. Thank you for this rich discussion today. We will be resending out the response form for the equity and business case, business data flow questions that we shared today in the hopes of getting further feedback from others who perhaps didn't have a chance to respond in the past week. We look forward to your presentation at our meeting next week and your involvement when we look at the develop and report situational awareness work. And with that, I will hand the mic to Janet for her final comments and next steps. Thank you all.

Janet Hamilton

Yes. Thank you so much. In the interest of time, I'll just echo Carolyn's thanks for a really robust conversation today and look forward to more in the future. And then, I will turn it over to our ONC folks to close us out and talk about the next steps and homework. Thank you all.

Next Steps (01:24:08)

Brenda Akinnagbe

Carolyn and Janet, thank you so much for leading this discussion today and thank you to all of the members for the great points and topics brought up. Like Carolyn mentioned, next week, we'll be looking at develop and report situational information. This is, actually, arriving at a very great time because, as we know, HITAC did also want us to look a little more deeply at how to respond to non-communicable disease emergencies as they arrive. To help us with the discussion on situational information for next week, we'll be sending out another set of survey questions on Friday. We ask that you get your responses back to us by 10:00 a.m. on Tuesday, June 15. Also, what we would like to do at this time is to extend the deadline for the survey that was sent out last week to give members a little more time to submit their responses. That,

too, would be due on Tuesday, June 15 by 10:00 a.m. So, we'll be sure to send out the links to both of those surveys to give each of you a chance to contribute.

That is all I have for today so thank you very much.

Michael Berry
Thank you, everybody, for joining us today. This is Mike Berry with ONC and we are adjourned. And we will see you next week. Have a great day.