Transcript

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

July 6, 2021, 10:30 a.m. – 12:30 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
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)

Cassandra Hadley
Today, we're going to have some continued discussion on the recommendations that will be presented at the upcoming HITAC meeting next week. Let me officially open the meeting with the roll call. And I'll begin with the co-chairs. Janet Hamilton.

Janet Hamilton
Good morning.

Cassandra Hadley
Carolyn Petersen.

Carolyn Petersen
Good morning.

Cassandra Hadley
Danielle Brooks. Denise Chrysler.

Denise Chrysler
I'm here and I will be needing to leave at 11:30.

Cassandra Hadley
Sure. No problem. Jim Daniel.

Jim Daniel
Jim is here.

Cassandra Hadley
Steve Eichner.

Steve Eichner
Present. Good morning.

Cassandra Hadley
Good morning. Claudia Grossman. Steve Hinrichs. Jim Jirjis. John Kansky.

John Kansky

I'm here.

Cassandra Hadley
Bryant Karras.

Bryant Thomas Karras
Good morning.

Cassandra Hadley
Steven Lane.

Steven Lane
Good morning.

Cassandra Hadley
Nell Lapres.

Nell Lapres
Good morning.

Cassandra Hadley
Les Lenert.

Les Lenert
Good morning.

Cassandra Hadley
Denise Love. Arien Malec.

Arien Malec
Good morning.

Cassandra Hadley
Clem McDonald. Aaron Miri. Larry Mole. Abby Sears. Sheryl Turney.

Sheryl Turney
Good morning.

Cassandra Hadley
I'm sorry. Who is that?

Danielle Brooks
Danielle Brooks is present. Apologies. Technical difficulties this morning.

Cassandra Hadley

Oh, no problem. Good morning. All right. Carolyn.

Opening Remarks (00:02:07)

Carolyn Petersen

Thanks, Cassandra. Good morning, everyone. I hope you all had a relaxing holiday and had some time to get out and do some of the things we haven't been able to do for a long time. We are going to be resuming our discussions of the recommendations, our draft recommendations that we've compiled to date. We'll be starting with the health equity group. It was something that we had hoped to get to last Thursday and did not. And then, we will continue into the funding mechanisms, policy infrastructure, situational awareness, and individual engagement topics. In reviewing where we're at with our ONC leads and my co-chair, Janet, we decided that we're going to work through as much of this as we can today. And then, whatever we are not able to discuss, we will move into a section at the bottom of the document indicating topics that we have talked about but not formalized specific recommendations about. That will give us the Thursday meeting to, gain, go through all of the things we've discussed and achieve consensus.

This is important because we will need to send this draft to the members of the HITAC on Friday so that they are able to review that before their meeting and our presentation next week. So, just a little bit of a map of the road of where we're headed today. I believe the **[inaudible] [00:03:38]** is going to bring the Google Docs up on the screen. While we're doing that, I'll pass the mic to Janet for her comments.

Janet Hamilton

Great. Thank you so much. And good morning, everyone. And I would just echo I hope folks were able to enjoy some time this weekend. I would also say a lot of folks have been adding comments into the document. And so, I was really happy to see that. And as we move forward in our discussion today, I think it will be critical that we look for gaps or any areas where we don't have alignment or we have concerns as we move forward into really trying to clean up the document and finalize the recommendations. So, I just really appreciate everybody's time and energy as we move forward into this last stretch and very busy stretch.

Danielle Brooks

Hello?

Carolyn Petersen

Yes, we're here. We're just waiting for our ONC partners to pull up the document large enough that we can all see it. It takes a little bit of maneuvering technically to make it work.

Danielle Brooks

All good. I just heard some echoing and I was like did I do something wrong. So, thank you.

Carolyn Petersen

No. At the top of your Adobe along the top next to where it says public health data systems, there is a little microphone icon. If you click on the drop down menu, you can mute your speakers and then, you won't get that feedback.

Danielle Brooks

Thank you so much.

Review Recommendations Under Consideration (00:05:55)

Carolyn Petersen

I know it's not real intuitive. We have up on the screen now the recommendations around the health equity data. And I'm trying to think about the quickest way to ensure that we cover everything we have here and still continue to keep things moving. This is broken out into a bullet list of several points. I will briefly run through them and then, we can get feedback of any changes we need. First, ONC should work to ensure consistent collection of agreed upon standards for race, ethnicity, disability, condition, and impacts, sexual orientation, language of choice or preferred language, gender identity, and data for SDOH through USCDI or other mechanisms to meet community identification needs. ONC should encourage CDC to identify the proper pathways for incentivizing the collection of race, ethnicity, language, disability status, and other health equity data elements. Third, ONC should work to ensure consistent collection of agreed upon standards for race, ethnicity, disability standards, sexual orientation, gender identity, and data for social determinants of health.

Fourth, ONC should work with the community and OMB to explore collection of existing categories of race and ethnicity within the OMB standards included in USCDI. Then, if you could move up slightly, I think there is a bit more. Fifth, ONC should encourage CDC to work with state and local public health agencies to align requirements leveraging USCDI standards and reduce variation across states for collection of race and ethnicity data. Finally, ONC should encourage the use of language of choice or preferred languages to improve access and foster public health, cultural competence in emergency response, for example, contact tracers matched to the cases' needs. Those are the six recommendations around health equity that we have. There is a bit more text in the document that spells out some of that but I think this is the place to start the discussion. And I see Steven Lane has his hand up. Go ahead, please.

Steven Lane

Yeah. Carolyn, good morning. I just wanted to comment that Bryant Karras, Steve Eichner, and I spent probably a total of five or six hours on the document. But because neither of them has access to Google Docs, the recommendations were put into a Word doc, which was sent back to the team, unfortunately, pretty late yesterday. So, rather than reiterate all of that, some of it was wordsmithing, some of it was substantive. I just want to encourage the team to find that and try to incorporate that as much as possible. I'm sorry you guys didn't get it in time to incorporate it prior to this discussion.

Carolyn Petersen

Thanks for doing that work, Steven and Steve and Bryant. I know that we had some discussion about getting the language right here. We will work to get that into the document today and, certainly, have it in place for our review on Thursday when we finalize. I thank you for that work. Let's go to Arien Malec.

Arien Malec

Thank you. I sent some comments in over the weekend as well on the race ethnicity documentation. The issue here, just for the full task force, is that you've got the OMB classifications but the prescribed vocabulary for that in USCDI is the CDC vocabulary. And it may be sufficient just to specify that the OMB categories are minimum but that we should use the full CDC **[inaudible] [00:10:14]** set and be able to exchange information there. And once we do that, once we clarify the interoperability requirements then,

the real challenge is making sure that full race, ethnicity, and multi-race ethnicity data are collected upfront because I believe right now the way this works is that you are required to collect, at a minimum, only the OMB standards but you can collect anything that's in the full CDC set. We just need to make sure everybody can send and receive the full CDC set and that people are, actually, collecting data off the full CDC set. So, thank you.

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

Danielle Brooks
Hello. A couple of things. So, I made a lot of comments inside of the document. One of the things, I think, we really need to do is go for consistency. So, if you go through the bullets, at some places like Letter A, you have race, language, ethnicity, disability, SDOH, gender identity, and sexual orientation that kind of needs to be repeated because as we read these recommendations, it feels like it should not be consistent. And we're looking for a consistent set of data. The other thing, too, is I think we need to look at the process for data collection. So, the current standard in the standards barrier of collection is self-reported data. And I think that's an important component because if we're looking at different mechanisms of where we're grabbing it from that has been one of the most difficult challenges is a poor source of data. So, census data or even signing up for Medicare and Medicaid. Those categories are so limited and often misreported that there are self-reported data issues in that.

I think that we also need to really hunker down on some of this language. And so, I put some comments in here about incentivization. So, I wasn't quite sure who that incentivizing body is if it's the collector or the person providing the information. But I think the incentive is on the collector and the position of the information is building that trust and privacy around that so that we, actually, have consensus data. I do think that I agree OMB is not sufficient. And so, we should look at the prioritization of ethnicity data over race data because that's, actually, going to get us closer to understanding the populations that are impacted. I also think that age should probably be listed in this as well. I did not see that as a call out from a health equity standpoint. And then, also really making sure that language is not looked at as an aside. I think during these kind of surveillance pandemic disaster responses, language is so critical because that's the first way that people understand information and can provide that information.

So, we should make sure that this is kind of peppered sufficiently across that. And then, as F has cultural competence, I really would like us as an industry to move away from the concept of competence because that's an impossible categorization. We should really look at the condition of cultural responsiveness. So, I do not need to meet the barrier of competence in your culture. I need to respect and be responsive to the needs that you have. And I think that important turn of the phrase is critical, particularly, in these emergency situations where we're, actually, looking at being responsive to those people and the demographic needs as well. And then, lastly, I put in the comments I know the disability section considers a lot of physical and sensory disability. But I do wonder about intellectual as well because, again, we're trying to get information and people to the right access to resources in this respect. And then, I know I have a lot of comments on this. This is the problem of being a health equity person.

The other thing, too, is, again, making sure that we hunker down on that privacy and transparency, not only in the sharing but the storage of data because remember, a lot of this data can be discriminatory data

depending on the state that you live in. So, we should really make sure that there is a federal guideline of standards to make sure that there is not only privacy protection but also recourse if that use is for discriminatory purposes. So, I'll stop there. I gave you guys way too much but happy to add additional comments to the documents if it's helpful.

Carolyn Petersen
Thanks, Danielle. Let's go to Denise Chrysler.

Denise Chrysler
Sure, thanks a lot. After Danielle, I don't think I can provide that kind of expertise. But here are some things I had noted. With regard to state law, ensuring that in my work with law and data disaggregation by race and ethnicity, I've learned that some states do not believe they can go beyond the OMB standards. I'm not familiar with the CDC set but now, it's clear I need to be. But supporting changes in law, there are many laws that have very restrictive data collection and encouraging broadening of law and interpreting and policy to meet the needs of the state, which for the second point is the national consistency recognizing both the need for flexibility and consistency and thinking, for example, the importance of being able to disaggregate and collect data, analyze data, report out data for sub groups and not just the broader classifications. And that's going to vary across the nation for American Indian populations, for example. If you're in the southwest, you have a need for substantial tribes and subgroups whereas if you're in eastern states, you may not.

And then, my final point I wanted to make is in addition to working with I believe it's ANC should encourage CDC to work state and local health departments, I'm looking for the language, but also remembering representatives of the particular groups that are being described. I know I've heard American Indian representatives talk about who is defining who is an American Indian, what membership means, how does that work for urban **[audio interference]** and that sort of thing. That's it.

Carolyn Petersen
Thanks, Denise. Let's go to Les Lenert.

Les Lenert
Yes. I wanted to just comment on the item AB that I added to this to just highlight. Part of the point of accessing this data is to ensure the people who have disabilities, mental, physical, other things can get access to care during an emergency. And one of the problems that happened with Katrina was the people in the community who were unable to move quickly enough were harmed or killed in the flooding. And so, public health ability to track the people who are disabled is really important in disaster response and in emergency response of all kinds. And one of the best or the most up-to-date sources for that data and there is a broad variety of them, often times Medicaid data on devices and other things that are associated with disabilities is the billing for that is very good data. But the EHR is a good source for that. And people need to be able to access EHR data for this purpose. So, I've added this recommendation as an approach to allow public health to be able to update their list rapidly and to work with clinical care to target those who have the greatest needs in these periods of urgency.

Carolyn Petersen
Thanks, Les. And I see Danielle has her hand up again. Go ahead, please.

Danielle Brooks

Sorry. I think that was, actually, in error. I apologize. So, I wanted to respond to one of the comments about the categorization, especially in the indigenous communities. I think that was a very important component. I think also just getting a standard definition of what race and ethnicity is is also critical because as I am championing for ethnicity over race, there are certain states, particularly Louisiana and Florida that consider Hispanic a race and not an ethnicity. And that needs to be cleared up because once you roll up that data, it's really difficult to compare from an analysis standpoint. So, I think there has to be clear definitions. And the community should be involved with the nomenclature if it's Hispanic, Latinex, Latino, however the community feels it should be involved with. The other component, too, that I did want to talk about and I'm not sure how this is reflective because this is very sticky, but this seemed to be predicated on individuals that are intersystem.

So, that means that you either have had a point of care or you are in some sort of entitlement program. But there are swaths of people that do not have a point of care and/or are undocumented. And in a public health emergency, despite any political considerations that is critical, especially if it's a contagious disease. So, it kind of begs the question of how do we support and serve those communities in a way, get surveillance data, and able to make sure that they are receiving access to information and care because that was another issue with the pandemic. And how do we make sure that they're able to receive those services without having that status come into play and be a barrier. So, I'm not quite sure how we want to reflect that but I think that is a crucial component as we consider this in an equitable standpoint.

Carolyn Petersen

Thanks, Danielle. Steve Eichner.

Steve Eichner

Thank you so much. I'm going to keep this really short. As Dr. Lane suggested earlier, he, Dr. Karras, and I worked together over the weekend to submit comments and really address most of our issues and concerns. I did want to highlight two things really quickly. 1.) Looking at training for asking questions about race, ethnicity, and disability and other status becomes, particularly, important to encourage individuals to share information at the level one is expecting so it could be recorded appropriately. Providing appropriate context is really key. And if we don't ask questions in a consistent manner, we're not going to get consistent answers. I think looking beyond physical disabilities becomes, particularly, important, especially if we're looking at how that data may be used, if we're looking at working with people in evacuation shelters, for example, if they've got a mental health condition that could be aggravated or impacted by being in a crowded environment. That's really worth knowing upfront so that the right services can be delivered at the right time.

And one tool to help collect information about disability status outside of the usual healthcare system are tools like emergency services registration or evacuation services registration that exists in at least some parts of the country for hurricane evacuations or emergency services. People have to be encouraged to participate in that. It's a voluntary registry. So, there is an educational component that becomes relevant but that is one additional source of information outside the traditional care network. And I'm going to state my oral comments in hopes that folks will look at the written material we submitted. Thank you.

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

Bryant Thomas Karras
Thank you. Can you guys hear me okay?

Carolyn Petersen
Yes. Go ahead.

Bryant Thomas Karras
One thing that I wanted to emphasize is in I think it's Letter E, encouraging consistency. I want to make sure that we don't gravitate towards the meaning. I think that a comment was made earlier that Denise Chrysler made that there is, potentially, variability and need for granularity and information in work that we've done. And I want to encourage this group and ONC to reach out to organizations like the Urban Indian Health Institute that is an epicenter that looks at the needs from an epidemiologic standpoint of identifying tribal members no matter where they're located. And we are a mobile society and we need to recognize that what may be a perceived norm may not be consistent. And we need to be able to recognize those at risk individuals no matter what state they reside in. So, I'm hoping that we can use this opportunity or these recommendations to help all of the data collection in all states reach the level of granularity needed to identify those types of issues and problems. Thank you.

Carolyn Petersen
Thanks, Bryant. Do we have any comments from task force members who are just on the phone and not in the Adobe? Okay. It looks like we have one last comment from Danielle Brooks. Go ahead.

Danielle Brooks
You guys are going to get tired of hearing me today. I do want to keep one key principle in mind as we look at standardizing the demographic data. Again, I am very much a stickler for always repeating the same categorizations, the demographic, SOGI, SDOH, race and ethnicity language. But we should also remember that what we are trying to attempt to do is to impact the end result. So, whoever the community is that's being impacted is the No. 1 thing. And so, as we look at the standardization of these standards, it's critical that we're doing it in a way that, actually, reflects on the ground and that we don't sacrifice or we don't place administrative burden over the actual work and how it will impact it. And so, in the space of trying to standardize this, it's so essential that we do get community input understanding and I agree that communities are mobile and there is a lot of intersectionality there. But overall, I think where we fail from a data collection standpoint is rolling it all up into this perception of everybody can be rolled up into one racial category or one way of looking at it.

And in reality, the smarter and granular that we can get with the way this, actually, impacted with the community and the community view is going to bridge those privacy issues, those concerns about trust, etc., the more that we get them involved in these conversations. Thank you.

Carolyn Petersen
Thanks, Danielle. I don't see that we have any additional hands raised or other comments so I will pass the mic to Janet to start the next part of our discussion today.

Janet Hamilton

Great. Thanks so much, Carolyn. And just one question, actually, before we move on to the next section and Steven, Bryant, and Arien, we really appreciate your work over the weekend. I was just wondering based on some of the discussions here that we've had this morning as well as your reflections on the work that you did related to this section, did you all comment at all on the need for individual engagement and how the systems may be able to support that in this section? I just want to be sure this health equity section is a bit of a crosscutting section. And so, I just wanted to see if there were reflections on that.

Arien Malec

This is Arien. I thought later on, and maybe I haven't read this in detail lately, but I thought later on we made recommendations that individuals should be involved wherever possible in supplying data about themselves. In particular, important and critical data such as the sort that we're discussing here. So, I do agree that, if my memory is correct and that information or that point is in this document, we should pull it up here. And if it's not, to your point, I think we should include it that we should allow individuals directly through electronic means and encourage consultation with clinicians and public health workers, etc., to be involved in the determination and collection of data about them.

Steven Lane

And this is Steven. I'm off the Adobe for the moment so I'm just going to chime in echoing what Arien said. And I think our little subgroup did provide comments in this area. I think it is really important that we move in the direction where individuals have the ability and the right to access the data that is collected and maintained about them within the public health infrastructure. And I think that the challenge is how to do that without excessively burdening public health itself. I think Steve Eichner can comment but there is a desire to not ask public health to stand up portals and maintain those for patients. But if we can make data available via API then, any patient directed app should be able to go and find the data that's necessary. The other key individual aspect that came up in our discussions is the whole issue of data being sent through the intermediary of an HIE and assuring that that data not be inappropriately repurposed beyond the public health purpose that it was being sent for.

And if there is a desire to allow repurposing of data that individuals have the opportunity to weigh in on that to provide either authorization to opt in or to opt out and figuring out how to accomplish that is going to be important because I think today, some of that repurposing is going on and patients have not necessarily had a chance to express their thoughts about that.

Janet Hamilton

Okay. Great. I appreciate you both reflecting on that. And we'll be sure that we get that captured. Thank you. So, we're going to go ahead and move on to the next section, which is a general policy section. And I would say, obviously, there is a lot about policy in this document. So, we did want to review what is collected in this section. There might be some opportunities to move some of these as well as if we think of the different sections within the document, this can also be a place where we are able to capture some broad, overarching components that maybe don't fit easily into one of the other buckets. So, for the group and for those on the phone, I'll read through these. I just want to make sure folks do go ahead and put themselves on mute please if you're not speaking. So, in this section, ONC should collaborate with CDC and ORC to

develop and release best practices 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 with the constraints that data provided for public health purposes may only be used for those purposes unless the patient has authorized other use of that data. And I think this, actually, dovetails well into the comment that we just heard. The second done, ONC and CDC should support policies that facilitate data sharing without data use for discriminatory purposes and ensure the appropriate level of access is provided with each level of public health authority. And ONC and CDC should support policies ensuring that secondary data use by other government agencies and partnerships complies with policy related to informed consent and other protections. The next one is ONC should collaborate with CDC, **[inaudible] [00:34:30]** and CSPE to identify ways to harmonize reporting requirements, roles, and capabilities across jurisdictions and states including data element, timelines for submission, and communication with providers.

The next one is ONC should collaborate with CDC, CMS, and other partners to explore levers to incentivize STLT, that's state, territorial, local, and tribal, use of systems that comply with federal standards for interoperability. Then, we have the next one being ONC should collaborate with CDC to identify an ongoing public health task force or work group with adequate authority to assess additional interoperability, connectivity, and information system needs relevant to public health. ONC should encourage CDC to elevate using existing task forces or groups to leverage this purpose to minimize burden. And then, we have the next one related to HIE reporting. I just lost clarity there. My screen looks blurry all of a sudden. I don't know what others are seeing on the screen. It looks like a digital cloud. But I'm going to move over. I have it up in other space. And so, hopefully, we can move on while the digital cloud catches up. And if it's my screen, hopefully, others can still things.

So, this one about HIE's, ONC should collaborate with CDC and other relevant partners to analyze and publish guidance aimed at educating states about state level policy and other barriers that prevent or impact public health reporting through HIE's. ONC should, additionally, collaborate with CDC and relevant partners to develop guidance on how data passing through HIE's for public health reporting can be leveraged for additional purposes. And then, there are, I think, two more. ONC and CDC should co-lead a certification body for public health standards with funding and participation from states. And then, we have ONC and CMS should invest in long term care and support services to incentivize EHR and health IT standards adoptions, be equipped for data exchange and reporting like heath systems are. So, for example, to expand the meaningful use and promoting interoperability programs. And it also indicates that ELR, ECR, and IIS should be explicitly included as standards for use. L

So, let me stop there and see if folks have comments about this overarching policy section. I will say we have not discussed it as explicitly in other meetings but the long term care component, I think, has, certainly, been an important component within this particular response and just would also offer if people wanted to make any comments there. And so, it looks like Denise Chrysler has her hand raised. Denise, go ahead.

Denise Chrysler
Sure. Just on the second bullet about ONC and CDC supporting policies where it talks about access for each level of government, it lists local, state, and federal. Could we also please add territorial and tribal?

Janet Hamilton

Yes, of course. Thank you. Other comments from the group? Bryant, I see your hand is raised. Go ahead, please.

Bryant Thomas Karras

So, I'm not sure if it belongs in policy or if it belongs in the section of research and advancement that we tabled for now. But I think that in parallel to the need for ONC and CDC to develop a certification process to ensure that public health systems are capable of meeting certain interoperable standard, there really needs to be an investment to advance these standards with participation from the public health community. I think that's one of the past policy levers would be to encourage that these standards and these requirements can't be advanced without appropriate public health representation on the big committees and standards bodies that are trying to advance these technologies. Thank you.

Janet Hamilton

Great. Thanks, Bryant. I think that's an important point that the standards development process is a consensus based standards development process and does include representation from public health. Let me just go to folks who maybe are only on the phones who want to make any comments in this more overarching section.

Danielle Brooks

Hi, this is Danielle. This may be a silly question but as we talk about public health, are we only defining them ion traditional structures? Are we also thinking about sometimes nontraditional structures that occur when there is a disaster? So, I guess what I'm saying is there are the traditional funded, even they're underfunded, public health structures. And then, there are the structures that turn into public health facilities. And is there a need to be any kind of policy considerations in that respect or somehow notating how we would support that in the event of testing or resource allocation?

Janet Hamilton

Thanks, Danielle. Do you want to maybe elaborate on that a little bit more? Are you thinking of groups that come in and start to help in a volunteer capacity? Or are you thinking more of some of the support that we saw that was stood up? For example, during COVID, we saw different types of pop up testing locations and things like that. And that was more of a healthcare function but in a new and different role. Or were you thinking of both of those?

Danielle Brooks

I was, actually, thinking of both. So, I'm thinking about **[audio interference]** that were turned into makeshift clinics, vaccination and testing distribution, standup groups. So, I'm in the Philadelphia area. There was a group that was funded, notoriously funded, but did not have the infrastructure and did a lot more harm than good here. So, I'm just kind of making sure we consider those kind of in between structures and how it fits within this data source component. The group I'm talking about was giving vaccinations to people that weren't registered and a lot of stuff like that. So, again, just considering how that malleableness comes into play during pandemic and other disaster responses and how we want to maybe shape policy regulations around that, particularly, as funding is allocated and also as data is trying to be exchanged.

Janet Hamilton

Thanks. If you have any specific language to suggest in that, I think it might be helpful. We haven't spent as much time talking about this. And I do think we want to get the appropriate incorporation of this sentiment but also be thoughtful about how we do incorporate something along those lines. Thanks for raising that.

Danielle Brooks
I'm happy to do so.

Janet Hamilton
Great.

Steven Lane
Janet, this is Steven Lane. Again, I'm still not on the Adobe. But there is this overarching theme that we're hearing over and over again, which is that ONC, potentially with others, should develop a certification program for public health systems. And then, we just had this discussion about long term post-acute care settings. And there have been prior discussions that ONC should consider a certification program for the health IT that's utilized in those settings. Clearly, the existing health IT certification came out of a period when there was abundant funding and that was taken as an opportunity to stand as what we have today, which has been so effective at moving the industry forward. And I think that within this, it would be wonderful if we took the opportunity of the current funding to see and help ONC to develop such programs for both long term care and public health. And I just hope that we can emphasize that in a unified way.

Janet Hamilton
Okay, great. That's a really critical point. Thank you for raising that. Any other comments?

Arien Malec
I raised my hand.

Janet Hamilton
I'm so sorry. Go ahead, please, Arien.

Arien Malec
I raised my hand late. So, on the policy point, which I believe is up here, there is a sentence with policy related to nondiscrimination or nondiscriminatory use. What I would encourage is that we develop a policy framework for data sharing for public health that ensures that data sharing for public health is used for appropriate public health purposes. Discrimination is just one of the many uses that public health data could be used for that would not serve or potentially not serve the interests of patients and individuals. And so, I just encourage us to think about a policy framework that allows data to be used for public health purposes in ways that facilitate data sharing and reduce concern with secondary data use. And this is an area where I'm mindful that the way that we've constructed public health authority in the US is state, local, territorial, tribal, etc.

This is an area where just like having a framework interoperability set of standards at the national level serves the interest of state, local, etc., authorities, having a policy framework that is universal and nationwide serves the interests of those regions, I would encourage people not to bend or alter that

framework even in areas where organizations have the authority to because every time we try to do local fleets, we end up impeding interoperability. Thank you.

Janet Hamilton

I think that's a really critical point, the secondary use of data and also the appropriate protection of data once it is submitted so that we can avoid adverse secondary uses of data re-release. So, that's a really excellent point. Thank you for bringing that forward. I am not seeing anymore hands raised. And so, I'm going to pass it over to Carolyn who is going to lead us through the next portion of the discussion. Carolyn?

Carolyn Petersen

Thanks, Janet. Being that we have had some discussion about situational awareness already, we are going to move to the individual engagement section. We haven't looked at that at all yet. I'll just wait a second while our partners scroll down to pull that up. So, we have seven recommendations here. I'll go through those briefly. First, ONC should work with appropriate HHS stakeholders to identify methods for providing more transparency regarding the collection and use of patient data. ONC should also work with OCR and CDC to establish more standard privacy guidance and to suggest standard individual centric language in messaging. ONC should ensure that patients can access complete information about where data about them has been shared and for what purposes. Second, ONC should explore partnerships with agencies outside HHS, for example, FCC, to resolve existing and future public engagement challenges such as screening of contact tracer calls to avoid suspected scams.

ONC should work to identify specific areas in which public health can use technologies to engage with patients. Third, ONC should explore delivery of relevant public health related information through patient portals, mobile device applications and other digital distribution channels to ensure that such information is available to patients and consumers in the same ways that they access other relevant protected health information. ONC should support the use of digital technologies that raise citizens' awareness of the importance of public health and/or facilitate compliance with public health guidance. Fourth, ONC should ensure that patients, family members, and caregivers have access to situational awareness data, including hospital capacity data to support their healthcare decision making. ONC should support the development of technologies that leverage alternative data sources such as evacuation data. Fifth, ONC should work with health IT developers to ensure patient portals have access to update key pieces of information by the patient like address, race, and ethnicity so missing data and information can be completed.

Plain language should be developed that provides education to the patient about the need for these data so they can be empowered to facilitate accurate collection and counting of their data. Sixth, ONC and CDC should work with health IT developers to ensure that public health data systems generate output in formats that can be readily understood and used by governing bodies at the state, county, and local levels. Leaders at multiple levels of governance that benefit from access to clear, granular data that support decision making at all levels and facilitate governance that supports public health needs. And seventh, ONC should support the use of plain language in communications related to access and patient privacy and data sharing to facilitate patients' understanding. So, task force members, go ahead and raise your hands in Adobe. Are there any task force members on the phone who have comments? Please go ahead.

Danielle Brooks

Hi, this is Danielle Brooks. I think the plain language, the last thing you read and I apologize that I'm not on the Adobe but, again, making sure that it is in multiple languages, there is a requirement for five percent for most accreditation bodies that your language outreach reflects at least five percent of your population. So, when you think about clear language, it's clear language but also preferred language. And that's the typical nomenclature. And I can go through the document and update it. But rather language of preference is the preferred language. So, it's preference or the language you speak first.

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

Arien Malec
My apologies if this is later down. But this is the place where I was remembering or maybe misremembering. This is also a place to re-emphasize the note that individuals should be involved in the process of supplying information about them, particularly, race, ethnicity, sexual orientation, etc., preferred language, information that the individual is the most able to supply. The second point, and this may be controversial, is the notion that we should apply the equivalent of the HIPAA right to individual access to public health information collected about the individual. And in particular, I'm thinking about immunization data from an immunization registry. But there may be other sources of data for which a HIPAA right to access or another way of framing this because these are often non-HIPAA actors is a FIPS right to individual access should be supplied to data collected on or about individuals.

And I understand that provides an additional set of requirements for states and localities who are collecting information about individuals. But this is an important way of making sure that individuals are involved in their own care, making sure that, for example, vaccination data is portable and accessible to the individual and also for raising trust in individuals in the public health system. Thanks.

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

Jim Daniel
Hi. I just wanted to echo a little bit about what Arien just mentioned about the immunization data. Is this the one place where we, specifically, call out consumer access to immunization data? I do think that should be a little bit stronger and, specifically, called out. It is, I think, one of the few areas where public health collects information that should be shared back with the public. I've mentioned that in another place last week and I wasn't sure that this was going to end up being the only place it is.

Carolyn Petersen
We have seven draft recommendations on immunizations. But I think they've been updated since I looked at it last night or early this morning. But if it's not noted there, we'll be sure that it gets captured here.

Jim Daniel
Okay.

Carolyn Petersen

We're getting a lot of changes all of a sudden in the document so it's a little bit fluid right now but thank you. Go ahead, Steve Eichner, please.

Steve Eichner
Yes. I think that we need to be cognizant of, as we're looking at connectivity **[inaudible] [00:55:48]** are a couple of things. 1.) We need an exterior set of guidance and supporting technology tools to manage access to data with an IIS for individuals like minors and families where there has been a divorce. And as one custodial and one noncustodial parent to identify who explicitly has access to a minor's records. Secondarily, one of the things that we're beginning to see and we're a little concerned about is looking at bulk queries or population level queries for data from IIS's and the number of queries and number of entities that could be requesting data in public health's ability to manage that from technology capacity perspective. If public health receives queries for entire populations from multiple HIE's as well as providers, we may not be able to fulfill those requests in a timely manner if we're looking at multiple requests for millions of records on a daily basis.

So, we need to work with providers and ONC and others to identify strategies to provide timely information about patients when they are going to see when it is useful for healthcare providers, whether it be 30 days before a patient visit for an update, 7 days before, and the day before or something like that. So, just managing traffic so that we're not overwhelmed with requests that aren't really being used on the other side in a timely manner. Thank you.

Carolyn Petersen
Thanks, Steve. Do we have any other comments from task force members? I don't see any hands in Adobe. Okay. Nell Lapres, go ahead, please.

Nell Lapres
Yeah. I just wanted to comment on that last comment from Steve. I, certainly, agree that I think there could be more thoughtful querying. But I do also want to make sure it's clear that using queries or some other mechanism to pull information about patient populations back into provider or population management system is important for patient outreach and patient care. And so, while there can be more thoughtful consideration about how to do that effectively, I do want to make sure it is noted that that is important information to have in an EHR population health system. And it's something that, I think, evaluating options from a scalability perspective on the public health side as well could help facilitate that exchange of data little bit easier.

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

Bryant Thomas Karras
One thing that struck me about this section and maybe it just needs to be highlighted a bit, it seems to focus on ONC exploring or ONC ensuring. And I feel like there are a couple of places that mentioned other agencies but I'm wondering if that needs to be carefully thought of. Does ONC have the partnership it needs to be effective in encouraging these individual engagement capabilities? One of the things and perhaps one of the things that could be emphasized here is resources brought forward so that states who are engaging with multiple languages, multiple communities are able to share or leverage translations that have

been done elsewhere for reuse rather than every state, territorial, and jurisdiction having to redo the translation of CDC guidance, for example, when the guidance is updated. Having to retranslate to keep current and consistent into every single language that you're engaging with can become a maintenance challenge.

I think some thought could be put into how best to maintain these engagements because it's not just a one time translation. It's ongoing, especially as guidance evolves. We need to have those translations ready so they're accessible to all communities at once. Thank you.

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

Steve Eichner
Thank you. I do agree that there should be continued work and collaboration between public health and providers to get the right information for multiple uses to providers in a timely fashion. We need to hit a good balance so that we've got the technical capacity to meet those requests. I guess the other piece to tie things back around is looking at tying immunization data back to equity, to a certain extent, to potentially leverage HIE's and other resources to get the missing data that we're seeing from organizations and other ways of collecting it rather than solely from providers. Can we leverage other data resources or equity and related data? We're not asking the patients the same questions time and time again. Thanks.

Danielle Brooks
The only thing I would say in context to that is that we just have to ensure that the source of data is the best source because it's not really regulated in a correct sense of guidance from OMB. But the harm in not getting that self-reported data is that it would be inconsistent across for measurement purposes. So, I would agree with that to kind of reduce administrative burden. But at the same time, we have to make sure that that's, actually, accurate the sources we're pulling from.

Steve Eichner
Absolutely. Thank you.

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

John Kansky
I believe this is relevant to the interchange that just happened. And I wanted to just add a little color. So, in a couple of states during the pandemic response when states were struggling to report race and ethnicity, whether that pertained to testing or immunization or anything related to pandemic response, in a couple of states, it was discovered that HIE's had race and ethnicity data that could enrich what the state already knew. In other words, filling in a lot of unknown blanks. All due cautions about where the data came from and patient matching and all of that absolutely. But I just wanted to make sure that that's not a hypothetical in a couple of states. HIE data was used to enrich, carefully, the race and ethnicity knowledge of the population. Thank you.

Carolyn Petersen

Thanks, John. I don't see any other hands raised among our task force members. Are there any last comments?

Janet Hamilton
This is Janet Hamilton. I just wanted to raise for the group to consider and comment on a lot of these recommendations are about plastering and supporting individuals to contribute their own data or have access to their data. And I think those are good. I'm just wondering about people's thoughts that might be related to pushing information to individuals and if folks felt like there were any specific recommendations around those lines. And that's a different kind of individual engagement. But sometimes, I think people have been appreciative when they have been identified and recognized that they may need X types of information or the ability for public health to be able to push out certain types of information. And I'm just wondering if anyone had thoughts on that piece in this section.

Carolyn Petersen
Steve Eichner, go ahead.

Steve Eichner
I think there is wonderful opportunity for public health to share information. In some cases, it may be a push but in other cases, it may be pull using tools like API's so that if an individual has an app on their phone and says, "Hey, update now," or when they launch the application it goes and queries for the latest data depending upon what the particular need or condition is whether public health is trying to send a notification from a contact trace or a proximity or versus looking at a vaccine update states. There are several different strategies that I think we can use. I think one of the advantages is using an API or something like that as opposed to establishing another patient portal is really trying to facilitate ease of access for individuals so that they don't have yet another place to go to find their information and perhaps looking at a way of encouraging centralization or reuse of that information whether it be through a patient portal they're already using at their primary care physician's office or Apple Health or Google Health Product or a third party provider or something like that.

Really the idea, I think, is to get it in the hands of the individual as efficiently as we can for individual use. Thanks.

Carolyn Petersen
Thanks, Steve.

Arien Malec
This is Arien. I'd like to jump in after that if possible.

Carolyn Petersen
Okay. Go ahead, Arien.

Arien Malec
Sorry about that but it's a really important point that if we were contemplating digital tools for exposure notifications, one of the weak links was being able to match lab result data to the individual. So, we should

also contemplate the sharing of data for individual access to positive lab data as an enablement for digital exposure notifications. Thank you.

Carolyn Petersen
Thanks, Arien. Let's circle back to Danielle.

Danielle Brooks
Thank you. One of the things, too, is that we do need to be cognizant that as useful that patient portals and third party apps like Google and Apple are important, the majority of individuals are still not highly adopting those uses. And portals are, usually, used inconsistently. In our practice, we see it mostly used for scheduling and not so much with the interaction as intended to. So, we should also consider tech solutions that may be low text. So, a texting program where people can engage in that respect just so that we make sure that, based on not only your comfort with the digital tool but also the accessibility of it and the universal use, a texting application would probably be more useful. The other thing, too, in these pandemic issues is that there is inconsistency, particularly with people that do not have a consistent phone number because they're using prepaid phones or they may be sharing a phone in an entire family.

We do have to consider those privacy considerations with this as well just because though we are talking about this in the guise of COVID, the nature of that response could just be individualized. So, along with these third party applications, what are some other ways that this information can get into the hands of individuals that may not have that resource or are high adopters of technology.

Carolyn Petersen
Thanks, Danielle. I would just add that I think some states are doing some kinds of the sort of data sharing/information sharing with members of the public. I know in Oregon, they have a daily mailing that you can get through email that talks about some of the specific pandemic related information like the number of new cases by county and specifics about deaths, age, county, date of diagnosis, and date of death as well as general health information that is relevant to taking care of yourself, ideas for dealing with some of the issues that come up around the pandemic. For example, how to handle the social distancing or being in lockdown and ideas for exercise and different ways of engaging with the family perhaps who you're not used to spending so much time with. That's an email, obviously, that's not a smart phone application but it is another way that individuals can access information and something that states are doing to get that out there.

Are there any additional comments in this area?

Bryant Thomas Karras
This is Bryant. I'm having difficulty raising my hand. One of the things that I think is worth exploring from an equity standpoint and from an engagement standpoint is rather than reverting to lower tech solutions we double down on trying to figure out how to get that accessible technology, smart phones, etc., into the hands of those who need it most rather than having to share a line. There are programs throughout the states, often times, funded through taxation on individual smart phone lines to provide free or discounted smart phone technologies to folks who otherwise couldn't afford them. And I think that getting the tools that do the job most efficiently into the hands of folks might be a worthwhile exploration, not discounting that we

need to make those lower tech solutions available. I think the digital gap may not be as unsurpassable as we think if we leverage the right resources. Thank you.

Carolyn Petersen

Thanks, Bryant. Are there any last comments from task force members? Okay. I'll pass it back to Janet for the next session. Thank you.

Janet Hamilton

Great. Thanks so much. So, the next section we're going to move onto is the situational awareness data section. And I will say, as we bring these up on the screen, there is some overlap here with some of the syndromic surveillance discussions. And I think I'll just try as we engage in this discussion to frame it a little bit that I think this section, as it is currently written, is really thinking more about additional types of data. I know within the public health world, we often think of our syndromic surveillance approaches as providing us situational awareness. And I think this section will, eventually, be next to or combined in some way with the syndromic surveillance. But this is really getting at things beyond some of the specific health data components that would provide public health this broader view of the environment and the situation. And so, just trying to help think about that within this framing and looking forward to the discussion and comments on this section.

So, I'm going to go ahead for the interest of folks who are only on the phone. This section is a little bit more verbose and I'll try to maybe paraphrase a little bit. And then, we can open it up for discussion. So, the first recommendation is that ONC should work with the public health community to prioritize adoption of new USDI data standards to consistently enhance reporting requirements to support public health responses. These data standards may include information available in or deliverable from information stored within the EHR systems as well as information stored in other systems used by healthcare providers such as inventory management. For example, supplies like PPE, medication, dialysis machines, ventilators, bed availability by type, staff beds, etc., staffing, management, equipment, repair databases, and other systems. Where appropriate, standards should be included in the USCDI. It may be necessary to clarify the rules of data class within USCDI that may not be required to be supported in all certified EHR systems but must be certified by relevant systems.

So, that's the first opener. And then, underneath that, there should also be standardized address information. I'm sorry. Can you go back up? Thank you. Collection and interoperability to facilitate geolocating and merging with census and other SOGI data. There is reference here to projects and other projects that may be leveraged such as USA. I'm sorry. What is the reference to that? Other projects like I'm not sure exactly what that's referring to. I apologize.

Arien Malec

Janet, that's a US postal addressing normalization product.

Janet Hamilton

Okay. US@, right. We might need to clarify what that is. To support patient matching, to appropriately issue similar implementation and conversion from social security numbers to Medicaid ID numbers or conversation from ICD-9 to ICD-10. So, that's the detail underneath that. I'm just going to go ahead and move on. There is another specific recommendation that ONC should coordinate with CDC, ASPR, and

state and local jurisdictions to define what healthcare status elements of information need to be available to support patient movement and resource allocation and develop preparedness plans specific to data needs and reporting requirements during high consequence public health threats. All stakeholders should be involved and consulted to define metrics, data definitions, standards, and procedures for triggering to enhance reporting and when it should subside or be discontinued. And the ONC should work with CDC to specify standard transport mechanisms so that public health receiving this data and the public health systems must utilize and I think it should say establish nationally defined metrics.

The next recommendation is ONC and CDC should work to ensure that FHIR based standards under development are flexible enough to capture multiple types of resources and data needs. This will allow standards to be utilized for unforeseen data collection needs during high consequence public health threats. And then, the next recommendation is that ONC should coordinate with CDC to support states in establishing shared infrastructure for collecting situational response data and public health data to support identified core public health data system functions. Infrastructure should exist at the state or local Health Department and/or through some type of centralized system such as HIE's or the APHL AIMS hub. And then, it lists some core functions here. And there are a number.

So, the core functions are about receiving, cleansing, de-duplication, about data aggregation, flexibility to add new types of data and queries, support for access for anonymized data and the development of AI or artificial intelligence tools, support of healthcare provider access, computational support to apply advanced decision making, ability to identify and help providers and government address health disparity issues, to provide data about the numbers and locations of vulnerable populations and communities, and to have some centralized dashboarding. There are some additional details there but I would encourage you all to review those. And then, the next recommendation is for ONC to coordinate with health IT developers, industry experts, and CDC to identify core functionalities needed within the EHR and inventory management systems, human resource systems, and other systems as needed to support all of these data needs necessary to respond to high consequence events.

And that ONC should coordinate within HHS to identify ways to incentivize the implementation of these functionalities. And these functionalities are specified in a list here. And I will paraphrase some of what is in the list. But calculation and reporting of core and aggregate metrics, identification of core public health data fields, support for transport mechanisms, notation of diagnosed cases, estimation and publication of routinely updated data on status and different types of status availabilities, severity for grading of cases, inclusion of demographic data and transmission, response and automated queries for completing case investigations, and follow up using FHIR and bulk FHIR forecasting information of future health status needs either 48 or 72 hours in advance. And also, strategies for integrating and transporting from clinical data systems. And then, the last one here is that ONC should explore levers for incentivizing the reporting of situational data by hospitals.

ONC should also explore certifying hospital based technologies beyond EHR's. ONC should ensure EHR certification includes functionalities required for public health operations and coordination of the health system among providers is in place, including responses to queries, including bulk FHIR and rapid deployment of point of care decision support activities. So, this is a big chunk of things. And I just want to open the floor up for additional comments on this section. Let's go first to Steve Eichner.

Steve Eichner

Thank you. At a very high level, I think one of the things Dr. Karras and Dr. Lane and I talked about briefly is that there really needs to be modifications to the USCDI or data that is logically in an EHR or can be derived from EHR data. There may be a second data dictionary for data that is not contained in an EHR like the number of ventilators or the number of cases of gowns or PPE or whatever. But those should be not included in the USCDI and not necessarily included in EHR functionality. Looking at defining the data needs and the appropriate systems should involve, not only experts in EHR technology but experts in inventory systems and the like as well as healthcare providers, ASPR, and public health. In looking at data collection, we might want to explore data collection from other entities or at least be able to support data collection from entities other than hospitals for this purpose. The focus was, certainly, on hospital level data and hospitals in response to COVID-19.

A future disaster might call for data from other entities in the healthcare environment, nursing homes, long term care centers, and the like depending on what the needs are and what services are required. So, you may want to keep an eye on that as well. Please refer to our written comments for additional information. Thanks so much. I'm sure other folks have some wonderful insights as well.

Janet Hamilton

Great. Thank you so much, Steve. Let's go next to John Kansky.

John Kansky

Thank you. Janet, going back to your caveats or clarification at the beginning of this section, you kind of inspired this comment is in contrasting syndromic surveillance with situational awareness, my understanding is that situational awareness in the public health context is a much more general and far reaching term. And it's apparent that this task force is we can't take on the entire world and boil the public health ocean. But a lot of our comments or our recommendations are specific to preparedness or high consequence public health event response. And I think that's fine and that may be totally appropriate. I would suggest that whether it be at the heading level of situational awareness for da-da-da or whether it be at the level of the transmittal letter to clarify what this task force is taking on and what we're not just so that I think it's totally fine to focus on one area and not another as long as we communicate clearly to whoever receives our letter. Thank you.

Janet Hamilton

Thank you, John. I think that's a really important point. And I know you brought up some great comments around noncommunicable diseases. And I, certainly, think about a lot of our framing and discussions have been about COVID. And I think that's because what we all have been focused on very recently. But, certainly, when it comes to noncommunicable diseases and even when you look at weather events and other things, we have seen a lot of adverse outcomes when it pertains to the impact on existing chronic conditions and the exacerbation of those when certain types of care is not available. So, when there are delays for getting oxygen refills and things along those lines or accessing dialysis centers, all of the exacerbation, lack of access to medications that are used to monitor certain critical functions, absolutely leads to major exacerbations of chronic illnesses. We really haven't addressed that in this document. Let's hear next from Arien.

Arien Malec

Thank you. This is a super technical point but the discussion of shared infrastructure at the national level should contemplate these multiple infrastructures. I don't think we're calling for a single shared infrastructure. So, as an example, we might have a state HIE but also have national query networks through the TEFCA. And we want to make sure that we have a policy framework that allows states and localities to access, for example, case investigation data and contact tracing data through the broad HIE infrastructure, not inadvertently call for the creation of a single piece of HIE infrastructure. Thanks.

Janet Hamilton

That is a critical component and key point. Thank you very much for raising that. Let's go next to Steven Lane.

Steven Lane

Thanks, Carolyn. I wanted to reiterate what Steve Eichner said. USCDI, as it exists today, has a very specific role to play in our interoperability ecosystem. And it is really the rule that is pointed to or the standard that is pointed to by the EHR certification system that exists today. So, in extensive discussions with ONC on this very topic, I think Steve's point is really well taken that we can include in USCDI or contemplate including in USCDI data elements for data that exists within the EHR that could be also beneficial for purposes of situational awareness. But there is clearly a lot of data in other nonclinical systems that are relevant here that probably don't belong in USCDI as it exists and the idea of a secondary set of data classes and elements specific to situational awareness that focuses on the data that may be outside of EHR's and other systems is really going to be quite valuable. And we should just be clear in our recommendations that those are two different things.

Janet Hamilton

Great point. And it looks like Bryant is giving that point a thumbs up. Let me just see if, Bryant, other than the thumbs up, did you want to make a comment as well? I know you mentioned you were having a little trouble raising your hand. Go ahead.

Bryant Thomas Karras

So, I just wanted to emphasize that and the previous comment that you agreed with that the assumption that a national, central HIE infrastructure or capability would meet the needs and may not scale well. And building off of successful state infrastructures may, in our hot wash of the situation, show their value. And perhaps part of the recommendation could be to have ONC, CDC, and others explore going back and reinvesting in those states that don't have the regional infrastructure to make sure that that's revisited. And then, on an earlier point around nonhealthcare situational awareness data, inventory management, for example, I'm not sure what the appropriate federal agency to point out, perhaps CDC but our strategic national stockpile capabilities and inventories and the purchasing power of those supply chains, I think, need to be examined as they can be put into place so that states don't end up competing for the purchase of needed supplies in response to future needs. Thank you.

Janet Hamilton

Okay, great. Thanks. And let me just check for task force members only on the phone.

Danielle Brooks

Hello. This is Danielle. I do have a comment. And one of the things that I don't think we've explored a lot with the creation of this is how do we screen for bias. So, it may be important int his section to consider, with some of these standards and some of this work, how do we look at bias screening in some of this work. One of the examples with recent COVID is that due to the trauma standards of prioritizing people, there was an unintended racial bias because people of certain demographics had comorbidities. And so, they were kind of linked differently and received less services based on their comorbidity status. And so, I'm happy to offer those comments making sure that we screen for bias when we're looking at these areas. And we have a process for recourse or attributing that. So, I'm happy to offer formal comments but I wanted to raise this for the good of the group.

Janet Hamilton
Great. Thanks, Danielle. Are there any other comments with any other folks on the phone? With that, I'm going to pass it back to Carolyn to read through the next section.

Carolyn Petersen
Thanks, Janet. The last section we have to talk about today is the funding mechanisms section. And if you're following along, that's on Page 10. And in this section, we have several that are fairly short. So, I will review those really quickly as a group and then, we can proceed. First, ONC should collaborate with CDC to encourage congress to appropriate robust, sustained, and consistent funding through the CDC to support development and maintenance of public health data systems and workforce capable of supporting both routine and large scale responses. Second, ONC should encourage CDC to develop plans for cross program funding of technology investments that support interoperability across public health platforms and the clinical care system, including alignment with TEFCA. Third, ONC should encourage CDC to allocate funding towards development infrastructure within health departments that can support common functions across public health program areas.

That would be things like centralized user management and single sign on to improve overall efficiency of public health. Fourth, ONC should encourage CDC to allocate funding for capability development like contact tracing that serves multiple public health goals separately from disease specific funding. There should be a minimum functional standard for public health that focuses not just on interoperability and standards adoption but also addresses infrastructure, expectations for scalability. Fifth, ONC and CDC should encourage incorporation of equity considerations into funding models. Sixth, ONC should encourage development in sustainable infrastructures and investment in useable architectures over time with rapid but more limited solutions. Such investment should aim to increase all states' capacity. And seventh, ONC should collaborate with CDC and CMS to invest in education campaigns, to enhance knowledge, and identify opportunities to incentivize professional development.

And with that, I am looking for hands in Adobe. Task force members, please raise your hand. Are there any comments from the phone?

Bryant Thomas Karras
This is Bryant. I think that the last point of encouraging workforce development is critical. I think that we saw a huge investment under meaningful use in re-educating or transforming available IT workforce to meet the needs of the health information technology efforts that were needed under HITAC. And I think we need

that same order of magnitude investment in generating the skilled workforce for public health. I know some activities are underway at ONC but I'd like to see those encouraged and amplified by other federal agencies.

Carolyn Petersen
Thanks, Bryant. Do we have comments from other task force members? I'll just give folks a chance to look on the screen. Go ahead, Steve Eichner.

Steve Eichner
I just want to re-emphasize the importance of, potentially, shifting policy to enable grading of funding at the federal level so that states and other jurisdictions that receive funding from federal government can lend funding from several different sources such as disease specific funding to implement single technology systems that leverage that funding to establish single instances of systems for functionality that can serve multiple purposes that could benefit both public health and providers. For example, we don't need multiple registration systems with multiple accounts or different accounts for disease for the same provider. We can streamline that if you can blend funding to implement once and reuse technology. That becomes really, really important. And I think the focus on the plan needs to be on planning for data collection. And that language needs to be clarified a little bit.

And if you refer to the written documents we've submitted, they're providing some guidance in that area. Thanks so much.

Carolyn Petersen
Thanks, Steve. Any last comments on this section from task force members? Seeing that we have a few minutes still before the end of our meeting, let's scroll down to the immunization section. You will recall we had our first discussion on this last Thursday. Perhaps we can very quickly review those and at least you'll be familiar with what's in the document that you may wish to comment on, even if we can't have a full discussion on this section. So, first ONC should work with CDC and STLT's to advance the further development of and adoption of the HL7 implementation guide both by provider systems and public health agencies to meet current and future immunization data needs. There are some subpoints under that. Second, ONC should collaborate with CDC, vendors, and public health jurisdictions to develop standards and implement infrastructure supporting. And here, we have a list of standards, including things like provider initiated multijurisdictional queries and enabling consumer access to IIS data.

Third, ONC should work with CDC industry associations and STLT's to identify a prioritized set of core data elements for providers to collect and report to public health. Next, ONC should work with CDC, STLT's, and industry associations to design a minimum set of IIS functional standards, which should include things like the ability to receive immunization data in agreed upon formats, accept messages using a standard transport mechanism, and so on. Next, ONC should work with CDC and industry associations, i.e., AIM and AIRA, to establish a certification process to bring all IIS to a defined minimum functional standard. And finally, ONC should work with CDC and legal organizations, for example, the Center for Public Health Law, to identify policies that are culturally preventing public health departments from fully interoperating immunization data with other systems and organizations within the walls of public health like the disease reporting systems and other industries.

So, that's a very quick run through on some things that came out on the discussion on Thursday. And let's go to Bryant.

Bryant Thomas Karras

So, maybe I'm misremembering but I feel like last Thursday, there was an agreement that advancing the scheduling capability, not just the reporting of the vaccine delivery itself to public health was something that needed to be recognized as a gap or a need to be put into place. I think we saw a huge variation across the country in folks' ability to get an appointment scheduled vaccine. And a centralized capability may not be the solution in that, for larger states that could become overwhelmed but an interoperable system that allows for that kind of scheduling needs to be developed and integrated into our vaccine supply chain capabilities.

Carolyn Petersen

Thanks, Bryant. Steve Eichner.

Steve Eichner

Just to re-emphasize what Bryant just spoke to. It's also connecting a registration system with clinical workflow for vaccine administration so that patients and providers don't need to re-enter data or get providers from a different system so that once I, as a patient or I as an individual, register for a vaccination event that information should flow through all the way through the event and to the IAS at the end of the day without re-entering by the provider.

Carolyn Petersen

Thanks, Steve.

Steve Eichner

I think the idea is we need to extend or revisit the existing implementation guide because there already is one that's been developed. It may not meet all of our needs. And it's focused on message based transactions rather than FHIR. So, I think we may want to explore at least updating the existing implementation guide as well as supporting other technologies like FHIR for integration, again, potentially leveraging HIE's or other providers or other entities as intermediaries.

Carolyn Petersen

Thanks. Let's go to Jim Daniel.

Jim Daniel

That was fast. I would just say under that recommendation for further advancing the implementation guide, I think it's worth calling out that there are some specific data elements like payer. I think it's on funding source and a couple of others around insurance status where there remains a lot of variability from state to state. And really honing in on those areas where there is still a lot of variability from state to state would be really helpful as we update the implementation guide. I think ERA and the immunization community has done an amazing job really standardizing and limiting the variability from state to state. But there are still probably three to five data elements. And I believe they all pertain to funding source or the immunization where we could use some better standardization.

Carolyn Petersen

Thanks, Jim. Let's go to Les Lenert.

Les Lenert

Thank you. I just want to emphasize that one additional functionality for IIS to have is to respond to population level queries so that providers can discover the patients that haven't been vaccinated. Here, we might call out the bulk FHIR standard to do this. But the main idea here though is that a provider needs to be able to present a population list of patients they have existing relationships with and get the status back for the entire group of patients at one time so that they can then look to complement the people who haven't been vaccinated. And that's the ones they should call, obviously, to go get them to be vaccinated. I think, currently, what IIS supports is transactions on a single individual by individual basis, which doesn't really help when you're doing the population function.

Carolyn Petersen

Thanks, Les. We still have a couple of minutes before we go to public comment. Are there any other comments from task force members? Go ahead, Jim Daniel.

Jim Daniel

I'll just echo Les Lenert's statement about querying for a population that's relevant to a provider and say that let's be maybe a little more general with provider in the language there. I think that recommendation was already there in some form because it's payers as well. So, there are other organizations that need to do that bulk query, not just to provider organizations but payers, employers, and others as well so just for the language there. Maybe have it a little more broad.

Carolyn Petersen

Thanks, Jim. And Steve Eichner.

Steve Eichner

We need to be cognizant of managing system loads as we discussed earlier and looking at what scalability is required and at what capacity do IIS's have to meet increasing demands or what flexibility do they have to increase their capacity in disaster response scenario. Thanks.

Carolyn Petersen

Thanks, Steve. And let's go to Bryant, please.

Bryant Thomas Karras

I'll make this quick. I think the comment has already been made. But those bulk querying capabilities need to be able to be done so in a way that doesn't bring public health systems grinding to a halt. And I think investment in the public health infrastructure or capabilities to support things like bulk FHIR have yet to be made on the public health side. So, looking for ONC or CDC to make that research investment implementation and roll out.

Carolyn Petersen

Thanks, Bryant. I will now pass the mic to Cassandra to take us into public comment.

Public Comment (01:51:34)

Cassandra Hadley
Sure. Operator, can you open the line for public comment, please?

Operator
Yes. If you would like to make a comment, please press Star 1 on your telephone keypad. A confirmation tone will indicate your line is in the cue. You may press Star 2 if you would like to remove your line from the cue. And for participants using speaker equipment, it may be necessary to pick up the handset before pressing the star keys. One moment while we poll for comments. There are no comments at this time.

Cassandra Hadley
Thank you. Carolyn.

Next Steps/Final Remarks (01:52:21)

Carolyn Petersen
Thank you. So, I want to say we've had a really wonderful day today in terms of circling back and picking out a few more points and refining these recommendations a bit more, getting us closer to our final draft. I know with the weekend and the readmission back into the work world, it's kind of a tough time to have an additional meeting. And I want to thank everyone for hanging in there and coming today and also putting your feedback and your adjustments into the doc itself. With that, I'll pass the mic to Janet.

Janet Hamilton
Great. Thank you so much. I really appreciate everybody's engagement and we have a bit to get done as we try to finalize things. But it's really been wonderful to see all of the activity and the work within the document. So, a huge thank you to everyone. We also want to talk about, and I'll pass it back to our ONC colleagues to talk about, next steps and when we can get final comments into the Google Doc itself. I think we do recognize that we need to lock things down and resolve any issues there. So, again, really huge thanks to everyone for all of your work thus far and I will turn it back over to our ONC colleagues to talk about next steps.

Brett Andriesen
Thanks, Janet and Carolyn. This is Brett Andriesen from ONC. So, if everyone can do any final edits in the document or comments or sending revisions to us on the ONC side by tomorrow at 12:00 p.m. Eastern, noon Eastern tomorrow, any final updates, at that point, we will lock things down and get things updated and turned around for our final meeting on Thursday morning.

Janet Hamilton
Okay, great. So, just to reiterate that for folks, we would like any final comments submitted by 12:00 p.m. Eastern tomorrow. And then, our intention on Thursday will be to not be able to go over new areas. There are a few areas that we did not have time to get to and we will have to reference those in almost like an appendix section at the end to say here are some comments that we did receive but we didn't get a chance to fully thrash out some of those discussion areas. And then, really to resolve any other outstanding issues and ensure that we have good consensus around the recommendations that we're going to be presenting and putting forward. So, let me just see if anybody has any questions before we close things out. Not seeing

any hands raised or hearing folks chime in from the phone, I will turn it over to our ONC folks to close out the call.

<u>Cassandra Hadley</u>
I think we're good to go. Thanks, everybody. Have great afternoon.

Adjourn (01:56:12)