

Health Information Technology Advisory Committee Public Health Data Systems Task Force 2021 Virtual Meeting

Meeting Notes | June 10, 2021, 10:30 a.m. – 12:00 p.m. ET

Executive Summary

The focus of the Public Health Data Systems Task Force 2021 (PHDS TF 2021) meeting was to continue to review feedback from TF members and to work to create a series of recommendations to the HITAC. The PHDS TF 2021 co-chairs, Janet Hamilton and Carolyn Petersen, opened the meeting, discussed the agenda and PHDS TF charges, reviewed the key pieces of feedback from the co-chairs' presentation to the full HITAC on July 9, 2021, and presented an updated scope for the TF's ongoing work. The TF reviewed a draft crosswalk document populated with information gathered by surveying TF members and from discussions held during previous meetings. PHDS TF members have recently provided feedback to survey questions on health equity and ideal business flow, and members were invited to discuss the topics and question prompts and provide feedback. TF members were encouraged to continue to respond to homework prompts. There were no public comments submitted by phone, but there was a robust discussion in the chat feature in Adobe Connect.

Agenda

10:30 a.m.	Call to Order/Roll Call
10:35 a.m.	Opening Remarks
10:50 a.m.	Review Recommendations Under Construction (Crosswalk)
11:45 a.m.	Next Steps
11:50 a.m.	Public Comment
11:55 a.m.	Final Remarks
12:00 p.m.	Adjourn

Call to Order

Mike Berry, Designated Federal Officer, Office of the National Coordinator for Health IT (ONC), called the meeting to order at 10:32 a.m. and welcomed members to the meeting of the PHDS TF 2021.

Roll Call

MEMBERS IN ATTENDANCE

Janet Hamilton, Council of State and Territorial Epidemiologists, Co-Chair

Carolyn Petersen, Individual, Co-Chair

Danielle Brooks, AmeriHealth Caritas

Denise Chrysler, Network for Public Health Law

Jim Daniel, Amazon Web Services

Steve Eichner, Texas Department of State Health Services

Claudia Grossmann, Patient-Centered Outcomes Research Institute

Jim Jirjis, HCA Healthcare

John Kansky, Indiana Health Information Exchange



Bryant Karras, Washington State Department of Health
Steven Lane, Sutter Health
Nell Lapres, Epic
Denise Love, National Committee on Vital Health Statistics
Arien Malec, Change Healthcare
Larry Mole, Veterans Health Administration
Sheryl Turney, Anthem, Inc.

MEMBERS NOT IN ATTENDANCE

Ngozi Ezike, Illinois Department of Public Health
Steve Hinrichs, Individual
Les Lenert, Medical University of South Carolina
Clem McDonald, National Library of Medicine
Aaron Miri, The University of Texas at Austin, Dell Medical School and UT Health Austin
Abby Sears, OCHIN

ONC STAFF

Mike Berry, Designated Federal Officer, ONC
Brett Andriesen, ONC Staff Lead
Brenda Akinnagbe, ONC Staff Lead

General Themes

TOPIC: OPENING REMARKS

The co-chairs opened the meeting, discussed the agenda and PHDS TF charges, reviewed the key pieces of feedback from the co-chairs' presentation to the full HITAC on July 9, 2021, and presented an updated scope for the TF's ongoing work.

TOPIC: REVIEW RECOMMENDATIONS UNDER CONSTRUCTION (CROSSWALK)

The co-chairs reviewed recommendations made to the draft crosswalk document that the co-chairs populated with information accumulated from the surveys/questions provided to PHDS TF members as homework, as well as from discussions held during meetings.

TOPIC: SURVEY QUESTION FEEDBACK AND DISCUSSION

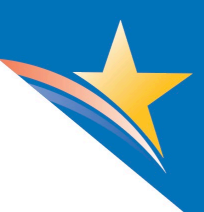
PHDS TF members have recently provided feedback to survey questions on health equity and ideal business flow, and TF members were invited to discuss the topics and question prompts and provide feedback.

Key Specific Points of Discussion

TOPIC: OPENING REMARKS

Carolyn Petersen opened the meeting and provided a brief overview of the contents of the presentation the PHDS TF co-chairs gave to the HITAC at its July 9, 2021, meeting. She stated that the HITAC was appreciative of the TF's work, and no major concerns were raised. Janet Hamilton welcomed members and thanked them for their engagement. The TF will discuss feedback from the HITAC meeting, including remaining gaps. Carolyn explained that the HITAC's responses were positive, and the co-chairs discussed the following topics, which were highlighted at the HITAC meeting:

- The idea that public health is part of the healthcare ecosystem, where data flow bidirectionally, was supported.
- Framework to create structural shifts is difficult to do, and TF members were challenged to re-envision new approaches in broader, more holistic ways.



- Funding for public health is important, but the PHDS TF will not be prescriptive in its recommendations (will not give specific guidance or try to build a budget).
- Landscape of communicable and non-communicable diseases should be considered (beyond COVID-19) when the TF makes recommendations.

Steven Lane commented that there is no obvious financial/business driver in place to create a more collaborative public health community/ecosystem, though there is funding to drive the state of public health forward in collaboration with the clinical side. Carolyn commented on related challenges and asked the TF to keep its suggestions within scope.

Carolyn reviewed the agenda for the meeting and the PHDS TF charge, which was:

- Charge – This Task Force will inform HHS’s response to President Biden’s [Executive Order on Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats](#).
- The PHDS Task Force shall:
 - Identify and prioritize policy and technical gaps associated with the effectiveness, interoperability, and connectivity of information systems relevant to public health. This would include a focus on surveillance systems, infrastructure improvements, health equity, clinical engagement, research and innovation, educating and empowering individuals.
 - Identify characteristics of an optimal future state for information systems relevant to public health and their use.

Carolyn presented the updated PHDS TF scope, which included:

- The HITAC PHDS Task Force's scope will focus on bi-directional data exchange between public health data systems and clinical data sources.
- This will include focusing on challenges, gaps, and ideal future state for data sharing between public health systems and clinical data sources (electronic health records (EHRs), laboratory systems, vaccine management software, operational, other relevant data sources).
- Topics previously in scope that now will be recommended for future HITAC discussions include research and innovation, social services data, and in-depth analyses of specific public health data systems.
- Recommendations and discussions surrounding health equity and patient engagement will be addressed in each topic discussed instead of representing unique topics for meetings and categories for recommendations.

TOPIC: REVIEW RECOMMENDATIONS UNDER CONSTRUCTION (CROSSWALK)

Carolyn explained that PHDS TF would continue to review the draft recommendations crosswalk document, which is based on the guiding questions shared with TF members and the feedback submitted by TF members as part of their homework. TF members who have not submitted feedback within the shared Google documents were encouraged to enter their information as soon as possible. She directed TF members to examine the draft crosswalk document, which was displayed in the Adobe meeting client.

Carolyn presented the draft recommendations crosswalk, which included potential gaps, opportunities, and recommendations for the following topics/questions across the target area of public health threat monitoring and investigation. The topics discussed at the previous meeting were included in the document, but the TF began by reviewing and discussing topics that were not covered previously. These topics included:

- Patient privacy, digital access, and social justice factors affecting key surveillance use cases
- Policy, licensing, and legal factors affecting key surveillance use cases
- Patient matching between public health and clinical systems



The PHDS TF will address the other target areas and remaining topics at future meetings.

DISCUSSION:

- Danielle Brooks commented on the first topic and stated that updates to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and other privacy updates do not fully address the need for a balance between data sharing and ensuring that public health data cannot be used by third parties or for discriminatory purposes. She mentioned the example that public health data from immigrant and refugee communities has been used by U.S. Immigration and Customs Enforcement (ICE) for discriminatory purposes.
 - Carolyn added that the recommendation should also address the secondary use of data by other governmental agencies and partnerships.
 - Janet commented that there is a need to ensure that the right level of access is provided to each level of public health officials (i.e., local vs. state vs. federal).
 - Arien discussed work he has done on the term “surveillance” and suggested that the public health community consider choosing a different term to avoid confusion or connotations around “spying.” He suggested that there should be a national framework for how public health data are used, including associated privacy protections.
 - Steven Lane discussed differences in the policy frameworks around required disease reporting versus case investigation versus clinical care. The minimum necessary requirement in HIPAA has to do with non-treatment-related exchanges with public health, so it primarily applies for the case of the investigation area, not in the care area.
 - Bryant Karras agreed that there are differences between the initial case report and a further, deeper investigation. He discussed how experiences during the pandemic informed public health and stated that the TF should consider public health’s role in clinical treatment and how to incorporate sharing of data with clinical partners into the policy framework. Also, he voiced his agreement with previous comments calling for awareness around use cases where identifiable data is shared by third parties, including with Federal partners (i.e., TSA/Border Patrol).
 - Denise Love commented on the application of minimum necessary and stated that better guidance is needed on how data are suppressed, aggregated, and reused (but not masked). She suggested that this could be an opportunity for funding data scientists at the local level.
 - Janet emphasized Denise’s points and stated that additional guidance might be needed on the use of data for surveillance, including where HIPAA applies and where it does not. Guidance can be provided on how the data can be shared and on detailed data for public health surveillance purposes (to be more explicit for more providers).
 - Carolyn agreed that the TF is well-placed to provide guidance. Understanding how HIPAA applies on the consumer side is often confusing and challenging.
 - Steve Eichner added that public health needs to get the data in a findable way. There is a balance between getting a large, all-encompassing patient record and focusing on the important details. The provider’s administrative burden must also be considered.
- Bryant Karras commented on the “Policy, licensing, and legal factors affecting key surveillance use cases” topic that the TF might want to deploy approaches used previously by the Association of Public Health Laboratories (APHL) and the Centers for Disease Control and Prevention (CDC) to provide technical assistance to connect electronic laboratory reporting to public health. He discussed that project and some of the resulting challenges and stated that a similar approach could be used to deploy standards for the collection of social determinants of health (SDOH).
 - Steven Lane stated that the current structures are permissive and allow providers to share data with public health, but the structures do not force the sharing of data. He suggested that the TF determine how to align with Information Blocking provisions and TEFCA to ensure that there is an expectation of data sharing, not just permission.



- Bryant asked Steven if this would be a declaration made by states, not the federal government.
- Steven responded that some jurisdictions were able to do this, but the work was not scalable. The burden was too great.
- Denise Love commented on the “Patient Matching between public health and clinical systems” topic to recommend that each state should conduct an inventory of existing infrastructure in their departments to determine what has already been put in place for linking data sources (i.e., health information exchanges (HIEs), other MPI technology). Public health should take advantage of the linkages that have already been made.
 - John Kansky voiced his agreement with Denise’s comments and stated that some solutions just do not work in all states. However, some HIEs are serving in global matching roles across an entire state (Colorado, Indiana).
 - Janet Hamilton stated that the intent is not to imply that there is not good matching. Rather, when information is shared, there is a minimum amount of data that should move to ensure that matching is occurring effectively and appropriately.
 - Denise agreed with Janet’s comments and stated that states must harmonize demographic data elements across data sets across the ecosystem. Robust patient identifiers are in place for some data sets but not others, so linkages are not as strong without them. Public health should work to be a bigger part of the process.
 - Arien Malec suggested that the wording should be changed to emphasize “exchange” and to move the phrasing from “minimum” to “core standard.” TF members shared several comments and suggestions for the wording, and Carolyn responded that the wording would be updated.
 - Danielle Brooks discussed issues with a lack of standards around reporting vaccination data from mass vaccination sites. She stated that non-clinically based entities need to have access to a standard repository for data.

TOPIC: REVIEW RECOMMENDATIONS UNDER CONSTRUCTION (CROSSWALK)

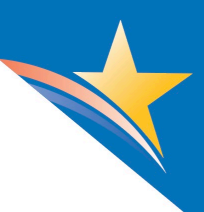
Janet explained that PHDS TF members have been providing feedback to survey questions on health equity and ideal business flow. Summaries of the questions were included on slides #8 and #9 in the TF presentation deck. Janet invited TF members to discuss the topics and question prompts.

DISCUSSION:

- Steve Eichner commented that the national data standards for describing disabilities are lacking, as opposed to the name of a disease or cause of a disability. He stated that this is especially important in terms of describing physical components of disabilities (i.e., not being able to raise arms). These data are necessary, for example, when evacuation services are necessary. He asked if a list of choices should be provided to the patient or if a more responsive/information gathering approach should be used. Patients might be concerned about prejudice when being asked questions about disability, but clear communication around why the information is necessary can help.
- Denise Love stated that some of the root causes for why equity-related data are not captured and/or reported to public health frequently today are linked to the design of systems (macro design issues and outdated lab systems). She suggested that there are cultural sensitivities involved, as well.



- Danielle Brooks agreed with the previous commenters but asked that “LGBTQ” in the survey question be changed to sexual orientation and gender identity (SOGI) data to capture more complete and robust data. Also, she asked that “primary language” be changed to “preferred language” (or that this is added after primary) and discussed preferences. She stated that the systemic standardization around the collection of data should change, and the TF should consider why data is being captured and for what purposes. She suggested concentrating on ethnicity over race. Also, she discussed how enrollment data can be unreliable and emphasized the need for an education campaign for consumers/patients and providers to help everyone understand the importance of properly capturing this information and explain how it will be used.
- Bryant Karras submitted comments on data collection but encountered audio issues. Carolyn asked him to provide links to the organizations doing the work he described on ethnicity categories, gathering more granular data, and updating databases.
- Denise Love voiced her support for subgroups within the broader health equity data categories to allow public health to design interventions and programming. However, she emphasized the need for states to be able to roll the new categories up to be useful in comparisons the past data/categories.
- Janet Hamilton encouraged TF members to consider the technology infrastructure that is needed to support testing in non-traditional locations.
- Danielle Brooks emphasized the need to use care when asking for race/ethnicity, SOGI, and demographic data. Individuals will be more comfortable providing the data when they are told where the data are housed and how it will be used. Trust building is essential, so there are opportunities to address patient privacy concerns.
- Denise Love stated that a holistic framework/system is needed to do a better job bringing different data sets, syndromic surveillance, and population data to use the data in a more standardized way. She referenced Dr. Michael Stoto’s work on this topic.
- Steve Eichner stated that it is critical to determine how to segment data to maintain patient privacy.
- Steven Lane stated that patients and communities should be called out as stakeholders, independently, and to consider the role of public education and public service announcements around the collection of data. Being clearer would be helpful to inform patients about how collected data can be useful.
- Bryant Karras commented that EHR certification is focused on minimum necessary, but he stated that the bar needs to be raised beyond this to get to the ideal state for public health.
- Steven Lane asked if the TF members’ answers to the survey questions would be captured and presented at a future meeting for all to review. Brett responded that all feedback would be included in the TF’s Google docs in the future.
- Steve Eichner suggested that HIEs and data resources could be used to augment the information that public health already has around race/ethnicity, disabilities, SOGI, and other sources. He discussed the advantages of HIEs to facilitate care and coordination and how they can be leveraged to direct a patient’s test results to their regular care team when a test is done outside their normal care environment.
- Denise Love stated that a subcommittee of NCVHS is working on some of these common issues and noted that they will be holding a listening session in August. She suggested that the PHDS TF work together to leverage feedback and solutions.
 - Carolyn agreed and noted that information could be used to develop the TF’s recommendations. Denise will share links and the Federal Register notice with the TF after it is published.
- Bryant Karras suggested that the TF make a recommendation that the EHR/electronic medical record (EMR) vendors need to elevate their testing and certification of the public health measures beyond the minimum. He stated that these often only address structure and do not validate content after the system is deployed and customized.



Action Items and Next Steps

As their next steps, the PHDS TF 2021 were asked to continue to respond to survey questions. Members who did not submit feedback were asked to complete the questions.

TF members were encouraged to review the draft crosswalk document and to be thoughtful about potential TF recommendations to the HITAC.

Public Comment

QUESTIONS AND COMMENTS RECEIVED VIA PHONE

There were no public comments received via phone.

QUESTIONS AND COMMENTS RECEIVED VIA ADOBE CONNECT

Mike Berry (ONC): Welcome to the Public Health Data Systems Task Force!

Larry Mole - Veterans Health Administration: Good morning everyone.

Jim Jirjis: Jim Jirjis here

Jim Jirjis: I have to duck out for 30 min in the middle of this meeting

Bryant thomas Karras: you two did a great job yesterday

Carolyn Petersen: Thanks, Bryant!

John Kansky: being sensitive to your comment about staying on track, Carolyn... what's the best way for me to submit so ideas about how we think about the PH data systems needs through a chorinc *[sic]* disease lens?

John Kansky: some ideas...

Arien Malec: likewise -- my metacomment here is that we need to see the health system as a system & build ph data sharing on that system

Denise Love: Much of public health consists of non-real time admin data (vital statistics, hospital discharge, now all payer claims databases, even Medicaid, surveys) as core data sets that provide denominators for PH and are separate from surveillance/lab.

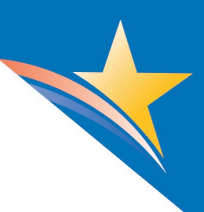
Steven Lane: The need for "non-real time" data is not unique to public health use cases. We have these clinically as well. I think that we should try to leverage interoperability tools and methods that have worked *[sic]* in the clinal and other realms rather than thinking about PH as an entirely new set of challenges to solve.

Janet Hamilton: this is an age old question - the perception of the use of the term surveillance- it has been hard to adequately define another term

Heidi Fox: Agree detailed data is needed to leverage reporting/surveillance across use cases

Steven Lane: If indeen *[sic]* PH surveillance is exempt from HIPAA, this is NOT well known in the clinical community and should be broadly advertised, e.g., by OCR.

Arien Malec: The point being that case investigation needs the EHR facilities to pull just the minimum necessary.



Steven Lane: The beauty of FHIR-based exchange to support PH use cases is that the true minimum necessary data can be exchanged.

Arien Malec: If all the EHR can produce is full USCDI, we have to declare that "minimum necessary" and that's the issue.

Heidi Fox:

<https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/publichealth/publichealth.pdf>

Arien Malec: Agree with Steve - if we use FHIR-based access, we can pull just the data PH needs for case investigation.

Steven Lane: Short of FHIR, providers are limited to the standard C-CDA documents or bespoke solutions, which at this point are burdensome and not scalable.

Heidi Fox: <https://www.hhs.gov/sites/default/files/hie-faqs.pdf>

Arien Malec: If there is one piece of advice for ph, it's that "just because you can require something *[sic]* custom and bespoke, don't believe you will be successful in doing so"

Arien Malec: If we design a system around system needs, we can design a system where PH gets what it needs without requiring custom work.

Bryant thomas Karras: thanks Janet,

Arien Malec: the history of public health is littered with public health specific standards or state variation of data requests and formats & it doesn't serve ph well.

Bryant thomas Karras: Paper from Denver health found that Mobile phone was most useful data element *[sic]* for matching...

Bryant thomas Karras: this is often not included in "minimum"

Steven Lane: Thanks for the great OCR links @Heidi! Can the ONC team add these as references at the bottom of our Google doc to make it easy for folks to find and download them?

Danielle J Brooks: May I accept a update: primary language should be defined as primary/preferred *[sic]* language

Danielle J Brooks: suggest* *[sic]*

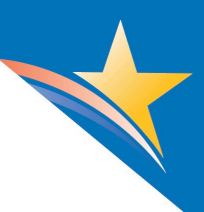
Steven Lane: Also LGBTQ should be referred to as SOGI

Steven Lane: Sorry - need to dial back in

Steven Lane: Back

John Kansky: I need to drop for another call. Thanks.

Steve Eichner: We need to be cognizant of the point of data collection. There is significant *[sic]* concern, especially *[sic]* among individuals with disabilities, regarding *[sic]* coverage for services based on their disability *[sic]*



Arien Malec: I'd note that the OMB costs are the minimum required for collection but USCDI allows the full CDC PHNVADS list.

Denise Love: If it was easy, it would have been done years ago.

Bryant thomas Karras: I think Taskforce should recognize and recomend *[sic]* continued investment in CDC and CSTE efforts to make improvements to SOGI and RE...

Molly MUrray: Community Health Centers collect a lot of these data, and capture/report on it via UDS reports annually. May be able to use their lessons learned or workflows to encourage collection of these data and reporting to public health

Carolyn Petersen: Bryant, are there URLs or other pointers you can post re: your earlier comments when there was audio trouble? We definitely want to capture that.

Bryant thomas Karras: @Arien again providers tend to do minimum and EHR EMRs just do what paying customer wants... we need the PHINVADS to be core/required to be supported

Mike Berry (ONC): We will open the call for public comment in about 5 minutes. To make a comment please call: 1-877-407-7192 (once connected, press "*1" to speak).

Denise Chrysler: Denise Love: who did you say you were "channeling" in your most recent comments?

Denise Love: Dr. Michael Stoto---he spoke at the NCVHS R/E panel and is at Georgetown Law and has worked with NAHDO on deidentification/statistical issues and is a tremendous resource

Denise Chrysler: Thanks, Denise. Sounds like a great resource.

Bryant thomas Karras: I think we need EHR EMR vendors to elivate *[sic]* their testing and certification of the PH measures beyond minimum. these often only address structure and don't validate content after the system is deployed and customized.

Bryant thomas Karras: Health care partners often customize systems into a non certified way

Bryant thomas Karras: ive called in on a clear line now.

Carolyn Petersen: Yes

Nell Lapres: @Bryant - providers are also asked to customize in non-certified ways due to state specific requirements. We should be moving towards more standardization across the board.

Arien Malec: The issue that Bryant notes here is not an EHR issue, it's an upstream LIS/Lab issue

Nell Lapres: Good point Arien.

Bryant thomas Karras: @Nell, most states follow national IGs but there are optional elements in the standard that EMRs often never implemented . these are not part of minimum cert but are in IG

Resources

[PHDS TF 2021 Webpage](#)

[PHDS TF 2021 – June 10, 2021 Meeting Agenda](#)

[PHDS TF 2021 – June 10, 2021 Meeting Slides](#)

[PHDS TF 2021 – June 10, 2021 Meeting Webpage](#)

[HITAC Calendar Webpage](#)



Adjournment

Janet and Carolyn thanked everyone for their participation in the discussions.

Brett and Brenda shared the ongoing timeline and work plan for the PHDS TF 2021, noting that the survey that was sent to PHDS TF members previously will be extended, and stated that the next TF meeting would be held on Thursday, June 17, 2021, from 10:30 a.m. to 12:00 p.m. E.T.

The meeting was adjourned at 11:57 a.m. E.T.