



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

Meeting Notes | May 20, 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 kick off the first meeting of the TF. The PHDS TF 2021 co-chairs, Janet Hamilton and Carolyn Petersen, welcomed members, discussed the TF's charge, and provided a recap of the key points raised during the public health hearing that was held as part of the May 13, 2021, HITAC meeting. The co-chairs led a discussion based on a series of guiding questions related to public health surveillance, which were included in the presentation materials. The TF will continue the discussion at its next TF meeting. 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/Public Health Hearing Recap
10:50 a.m.	Review Surveillance Discussion Guiding Questions
11:20 a.m.	Discussion
11:45 a.m.	Next Steps
11:50 a.m.	Public Comment
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 10:30 a.m. and welcomed members to the second 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

Nell Lapres, Epic

Les Lenert, Medical University of South Carolina

Denise Love, National Committee on Vital Health Statistics



Arien Malec, Change Healthcare
Clem McDonald, National Library of Medicine
Larry Mole, Veterans Health Administration
Abby Sears, OCHIN
Sheryl Turney, Anthem, Inc.

MEMBERS NOT IN ATTENDANCE

Ngozi Ezike, Illinois Department of Public Health
Steve Hinrichs, Individual
Steven Lane, Sutter Health
Aaron Miri, The University of Texas at Austin, Dell Medical School and UT Health Austin

ONC STAFF

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

General Themes

TOPIC: OPENING REMARKS/PUBLIC HEALTH HEARING RECAP

Carolyn opened the meeting, reviewed the agenda and PHDS TF charges, and provided a summary of the various panel discussions that were presented during the Public Health Data Systems Hearing hosted by ONC/the HITAC and the Centers for Disease Control and Prevention (CDC) on May 13, 2021.

TOPIC: SURVEILLANCE DISCUSSION/NEXT STEPS

The co-chairs led a discussion based on a series of guiding questions related to public health surveillance, which were included in the presentation materials. The TF will continue the discussion at its next TF meeting.

Key Specific Points of Discussion

TOPIC: OPENING REMARKS & PUBLIC HEALTH HEARING RECAP

Carolyn Petersen opened the meeting, reviewed the agenda, and discussed 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 provided a summary of the various panel discussions that were presented during the Public Health Data Systems Hearing hosted by ONC/the HITAC and the Centers for Disease Control and Prevention (CDC) on May 13, 2021. Janet directed TF members interested in viewing the presentations and a transcript of the meeting the HITAC hearing and meeting webpage, which is located at <https://www.healthit.gov/hitac/events/health-it-advisory-committee-34>

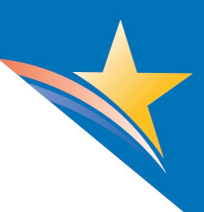
Carolyn shared several main points from the hearing, including the need to build a system that manages



everyday needs while also managing pandemic or other large-scale disaster needs. More transparency with the public around all public health work, including privacy and security, is needed. Health equity is a critical item that also needs to be addressed. Carolyn stated that it will take time for the public to develop trust. Janet highlighted the need for an infrastructure that works all of the time, and that can be scaled up. Also, the need to modernize the way business is done and to share data between health care and public health more efficiently was emphasized during the hearing. Public health systems are lacking the granularity of data needed to appropriately track public health actions, outcomes, control measures, and effectively communicate with the public. Janet explained that public health does not get data fast enough during their response, and incomplete/missing data impedes their work. Resource management is not well integrated and can negatively impact public health responses. Finally, she stated that the PHDS TF should analyze which activities are in-scope and which are not, given the timeframe for its work, and she recommended that the TF consider recommending the formation of a standing public health group. The co-chairs thanked Aaron Miri for chairing the HITAC meeting.

DISCUSSION:

- Arien Malec shared several additional key points from the public hearing, which included:
 - The funding mechanisms have led to the stovepiping of public health responses by disease states, and this has impeded wholistic responses and prevented infrastructure for things like contact tracing from being scaled up effectively.
 - Public health is a system, and this system needs to be funded and incentivized (for providers) so that there are the same standards and interoperability for state systems. He discussed work the Interoperability Standards Priorities Task Force (ISP TF) did on examining standards for Orders and Results in the U.S., which formed the basis for recommending improvements to clinical workflows, and he suggested that the PHDS TF be mindful of how improvements to the clinical workflow will impact public health responses.
 - The PHDS TF should consider funding, incentives, certification requirements, and mandates all in concert to ensure that healthcare infrastructure is fully supported to get data flowing properly for public health response needs.
 - The future public health data system should consider information systems that harmonize healthcare and public health, especially with regard to work on social determinants of health (SDOH) and chronic disease management.
 - Janet responded to Arien's comments, noting that many pieces resonated with her.
- Bryant Karras described his impressions from the public health hearing, which included:
 - He encouraged the PHDS TF to delve into topics and to examine the architectures in place beneath different states' public health responses. Some approaches may be difficult to reproduce.
 - Siloed funding for public health has led to a lack of overarching coordination between different program areas. Funding cuts over the past years have affected shared resources; they should be seen as a requirement, not an option.
 - State and organizational participation in national activities (standards bodies, HL7, workgroups and committees, etc.) are lacking, and this is connected to the lack of adoption of modernization efforts by public health.
 - The PHDS TF has to try to catch up with work that should have been done in the past that was not completed.



- John Kansky stated that he was impressed by the diversity of perspectives at the hearing and emphasized the need for a future public health system that works every day, as well as during emergencies. He highlighted comments from the hearing that a public (possibly government-run) option could be linked to the Trusted Exchange Framework and Common Agreement (TEFCA), while others suggested using existing interoperability ecosystems like national frameworks/networks/health information exchanges (HIEs). Others advocated for leaning on the future API capabilities of electronic health records (EHR) systems nationwide. He stated that because these are not necessarily compatible viewpoints, he looks forward to the debate.
- Clem McDonald discussed issues around not getting patient registration information and noted that these issues are due to laboratories in the Electronic Laboratory Reporting (ELR) system for public health only receiving specimen numbers, not the patient information. Additionally, the infrastructure for electronic case reporting (eCR) is incomplete.
 - Janet thanked him for his comments and suggested that the PHDS TF discuss lab issues at a future meeting.

TOPIC: SURVEILLANCE DISCUSSION

Carolyn explained that PHDS TF would hold discussions based on the surveillance guiding questions at the current and next TF meetings and directed TF members to examine the questions listed on slides #7 through #10 of the presentation materials. The questions were centered around identifying major gaps in data standards and key surveillance use cases (including but not limited to Testing, Case Reporting, Syndromic Surveillance, and Immunization), barriers to the sharing/use/linking/integrating of data from a variety of perspectives, addressing health equity concerns in relation to surveillance systems, and concerns related to eCR.

Janet moderated the discussion around the guiding questions and encouraged TF members to discuss the use cases listed or to suggest additional ones based on their experiences during the COVID-19 pandemic.

DISCUSSION:

- Jim Daniel commented on behalf of providers and discussed challenges related to variations that remain among states, even despite all of the work that has been done towards interoperability over the past decade. The public health community has gotten rid of a lot of variability, but what is left causes issues for providers as they try to connect to systems, like those used for immunization data. As systems are modernized, implementation guides (IGs) should be made stricter but also to be usable across the entire U.S., even if variations are required by states' laws.
- Arien stated that the failure is related to the use of standards, not the existence of standards. He discussed issues commercial labs have had with capturing certain demographic data and suggested that these issues are tied to billing requirements, not asking for enough/the right data. He stated that enough work has been done on the standards but that incentives are not in place for labs or providers to use the completed IGs. Incentives and funding mechanisms are also lacking for ADT-based (HL7's Admit Discharge Transfer message) surveillance and enhanced chart-based surveillance. Hospitals that primarily serve the underserved populations need funding to implement IGs and get information to public health systems. He suggested that eCR could be used as a case reporting standard and as a surveillance standard, with appropriate triggering conditions, and that the TF could examine replacing reportable conditions standards in the CDC IG with a single eCR standard, with more flexible trigger conditions that flow down to EHRs. Infrastructure for sending triggers to all hospitals is needed.
- Clem commented that all of the topics/questions should not be lumped under "surveillance." Also, he stated that the issues with the current state of ELR and eCR are tied to how systems share patient information between labs, hospitals, and public health. The TF must acknowledge that changing the process will require a lot of work.



- Larry Mole commented that the TF must consider the intent and the use of data from authoritative sources (more complete data set) versus data from labs. Also, he stated that there are differences in data quality and data use when public health is patient-centric versus population-centric. The TF should consider which approach they will take when addressing gaps. He asked the TF to think about how surrogate markers and alternate sources for data fit into ongoing influenza-like illness (ILI) work, and he addressed several examples used during COVID-19 relief efforts. Improve the way codes for identifying and tracking populations are rolled out (ICD-10, etc.).
- Les Lenert discussed how emerging standards, like HL7's Fast Healthcare Interoperability Resources (FHIR), offer new opportunities for public health to integrate with the healthcare system by changing the directionality and ability to capture data on cases that evolve over time. He explained how a trigger, like a lab test or order sent to data system-enabled public health, allows for the completion of missing data for testing cases. Public health needs to receive both the numerator and denominator for the notification of testing. Similarly, eCR for public health benefits more from the ability to query the clinical system using the FHIR standards-based approach than through a one-time trigger from an EHR. The TF should think about standards that allow the transmission of textual information directly to public health to conduct syndromic surveillance (ADT surveillance, which occurs before codes/standards are generated). Immunization registries should also be given the ability to use bulk FHIR to allow providers to access patient population data, prioritize care, and direct outreach efforts to entire populations, not just a patient at a time, as the system is currently set up.
- Jim Jirjis echoed the other TF members' comments about using FHIR and incentives and commented from the perspective of a provider that point-to-point solutions are burdensome and are not effective for a healthcare system operating across 20 different states. Also, he asked the TF to encourage a real endorsement of IGs and discussed examples of how different states interpreted blank fields. He stated that Meaningful Use had some incentives (only directed at the provider), but many states still have not implemented standards. Public health, lab systems, and states must be incentivized to adopted IGs.
- Danielle Brooks discussed the timeliness standards that impact the payers and described how the timing of and inconsistencies between the ways different states' health departments sent data affected her organization's ability to understand the scope of the impact, who was impacted, and geographical access. Standardization can allow for a better outreach effort, especially for those participating in Medicare/Medicaid services.
- Bryant discussed how states worked together, eventually with the CDC, to change standards over the years led to the creation of syndromic surveillance. He stated that this process will happen again, but the TF should work to ensure that space is left for innovation while encouraging the use of IGs and standards. He stated that public health has bad data around race/ethnicity and sexual orientation, and gender identity (SOGI) because the supporting standards have not been recently updated, so the TF should recommend investing in resources national organizations that will improve, evolve, and maintain these standards.
- Steve Eichner built on Bryant's statements and stated that harmonizing standards across data collection should continue. Also, the TF should consider what public health can return to the provider community (new data, analytic services, etc.) so there is shared value in data exchange. The TF should also consider which stakeholders are involved in particular kinds of data collection and discuss how to create standards that support leveraging previously collected data and HIEs to prevent recollecting data and to make the minimum amount of modifications to systems while still enabling them to share necessary data.
- Denise Chrysler asked about linkages between laboratories and public health for case reports and lab reports. Because labs do not need all the data available in the EHR, lab reports are more likely than case reports to be shared with public health. How can they reconcile this issue?
 - Janet responded that public health uses matching, and this process is harder when a lot of information is missing. Often, the lab report is the only item that is received, and public health spends a lot of time trying to fill in the pieces. The TF has an opportunity here.



- Jim Jirjis commented that there is a need during public health emergencies to create data standards that lab companies can adhere to and quickly enforce. Mapping changes due to shortages or necessary changes in methodologies during the COVID-19 response efforts often became burdensome, and he described some of the challenges his hospital faced with sharing this information, including the need for staff to manually enter and review patient/testing data to apply value sets/report.
 - Bryant responded to Jim's comments and described how Washington's state lab pivoted to be able to send outbound COVID-19 test results through the HIE to every emergency department within the state. He stated that there was a lot of initial resistance to this method at first because public health had not shared information in this manner in the past, but it ended up being useful. Unfortunately, Oregon had laws in place to prevent information from flowing in this manner, which created difficulties. Variations between states can be challenging.
 - Janet responded that a similar issue happened during H1N1 and Zika with returning results. These issues could continue in the future.
- Denise Love commented that the sharing, linkage, and integration of data is hindered by the lack of identifiers/patient identity, in addition to the long amounts of time necessary to get agencies aligned in these efforts. It becomes even more difficult when working across states.
- John Kansky stated that many policy barriers within each state should be easy to fix, including immunization registry rules for sharing data. He explained that another issue arose when hospitals thought they were not allowed to share data with HIEs and asked for the governor to give an order that an HIE should be an agent of public health.
- Jim stated that another burden he encountered was variations in state policies for sharing and reporting data, including one state that added over 60 additional questions with different data definitions from the federally defined data set. Business requirements were posted at the state and federal levels that did not have data/informatics definitions. These issues need to be addressed for data to be successfully shared.
- Nell Lapres echoed Jim's comments about who is responsible in government for collecting data and emphasized the need for clearer data definitions and metrics. Consistent patient matching logic and patient identifiers are important for public health across states/agencies, will break down silos, and will provide opportunities to provide the best patient care.
- Sheryl Turney explained that the current immunization registries (including the submission process and legal agreements) are set up for data submitters, not for data use and sharing. Guidance in these areas is needed. Legal rules across states for patient matching and data use are different, so leveling needs to occur across the ecosystem.

Action Items and Next Steps

As their next steps, the PHDS TF 2021 were asked to answer the initial set of public health surveillance questions for discussion and a follow-up set of questions. The links to both sets of questions were provided to TF members via email, and TF members were asked to submit all responses by no later than 10:00 a.m. ET on Tuesday, May 24, 2021. This will allow the ONC team to compile responses for inclusion in future meeting materials.

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): Good morning, and welcome back to the Public Health Data Systems Task Force meeting. We will be starting soon.

Jim Daniel: I'm here fro [sic] for roll call but still getting on audio

Carolyn Petersen: Thanks, jim.

Claudia Grossmann: sorry.. here. getting on audio

Carolyn Petersen: Thanks, Claudia.

clem mcdonald: Clem is here. But have not called in yet to get voice access

Brett Andriesen (ONC): Link to 5/13 Hearing materials: <https://www.healthit.gov/hitac/events/health-it-advisory-committee-34>

Bryant thomas Karras: I'm now on Adobe too...

clem mcdonald: Hear! Hear! Arian. The funding stove piping is the main problem

John Kansky: +1.... stove pipe funding and approaches are a problem

Jim Jirjis: Jim Jirjis Joining late

Sheryl Turney: Joined late sorry

Arien Malec: APHL for me is the model, rather than a Federal run option.

Arien Malec: @clem, this why I'm pointing out our lack of an ordering infrastructure -- if we had the HL7 LOI standard in place more universally, labs would get demographic/contact information.

Bryant thomas Karras: Yes Carolyn and Janet, sorry if i went on too long... pent up thoughts from last week...

Steve Eichner: In addition to improving how data may be available to public health, including, including what services/data can be returned to health care provides may serve as additional incentives to participate in exchange.

Jim Jirjis: Here here.

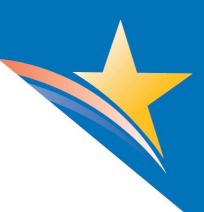
Nell Lapres: Completely agree. Not just between healthcare providers and public health but this could also impact the ability for cross-jurisdictional exchange of data as well.

Denise Love: is it a failure of enforcement and compliance and who has the authority to enforce for lab reporting?

Bryant thomas Karras: Yes and SOGI and Race Eth has not kept up...

Arien Malec: CMS has "enforcement" on payment policy, and CLIA has enforcement on the labs, but neither mandate standards use.

clem mcdonald: Thinking of sources other than hard medical data. Geat [sic] ideas !!



Denise Chrysler: I just compared Michigan administrative rules regarding physician reporting and laboratory reporting. Physician is required to report demographic details (inc race and ethnicity), lab is only required to report basic contact info re patient.

Denise Love: It is difficult to capture data directly from physicians; that's why many states have hospital discharge and all payer claims data bases to get broader system data/denominators.

Jim Jirjis: Len +1

Bryant thomas Karras: @Denise ... compare to WA State Board of Health rules that now require more detail than fed standards can code

Denise Chrysler: Will do. So many jurisdictions, so much variation!

steven: Steve H Here. The meta data lab receives is limited, some orders only include patient name plus one other identifier and the test requested. Progress is occurring *[sic]* but needs to be mandated for the labs to have a full data set.

Leslie Lenert: Jim--what is needed is an approach *[sic]* to re engineer public health systems to minimize variations

Arien Malec: @les -- constant *[sic]* & flexible funding over time + required standards implementation with certification & testing.

Arien Malec: HELP committee has draft legislation to this effect.

Noam Arzt (HLN): It is not that PH systems are ENGINEERED for variation - they are not. Current POLICY makes the variation IMHO.

Leslie Lenert: @arien: agree--one thing has been missing is a certification process for public health data system

Arien Malec: Then CDC & PH needs to stop being an island by policy. E.g., we don't need CDA guides for each reportable condition; we need something like eCR + flexible triggers.

Arien Malec: (I'm getting triggered here, the CDC standard for race/ethnicity is fine enough -- but the data ain't following). *[sic]*

Arien Malec: (flowing)

Arien Malec: Would be interested to identify from @brian what's a gap in the CDC standard for race/ethnicity?

Arien Malec: (@Bryant -- sorry)

Bryant thomas Karras: yes @Bryant... don't forget the "T" it is in the imp guide

Leslie Lenert: If a positive lab test is a trigger for a query to the clinical care system for data...

Arien Malec: (Actually eCR got to public health faster than labs did, mostly b/c labs were so far behind on COVID-19 RT-PCR testing).

Bryant thomas Karras: Agree that we need "certification process for public health data system" like ONC CHIT but there is not the same incentive that MU had for EMRs



steven: the challenge is to make ithe *[sic]* process automated, currently PH and the county or state epi must follow up personaaly *[sic]* and that delays the overall investigation

Danielle Brooks: Good morning everyone. Thank you for the great conversation. I will need to jump off early today. I look forward to continued work

Arien Malec: Right, that's why "certification" needs to be associated with consistent and adequate funding over time.

Leslie Lenert: Agree with @Bryant--certification is coupled incentive payments works

Leslie Lenert: certification must be coupled WITH incentive payments to work

Bryant thomas Karras: Can I make a comment on PH sharring *[sic]* COVID res

Jim Jirjis: Bryant. it would be awesome to have such a solution ready writ large across the USA for the next emergency

Jim Jirjis: In our 20 states we had multiple testing situations: public health state testing, multiple labs, in house testing, etc. and these rapidly *[sic]* changed depending on resources

Leslie Lenert: There is a real role for HIEs in distributing lab results in this kind of chaotic circumstance

Jim Jirjis: John, love the guitars.

Bryant thomas Karras: I was thinking Denise Chrysler could comment on state to state results

Jim Jirjis: Consider writing a public health modernaization *[sic]* song!

clem mcdonald: jim dont apologize. Your comments are all informative , good and uesful. Keep them coming *[sic]*

Arien Malec: The technical policy issue is the HIPAA exemption for public health authorities, but without clean delegation of PH authority to HIE or intermediaries.

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

Jim Jirjis: Thanks Clem

Steve Eichner: I agree that clear, coordinated communication regarding what data is required, and when rreporting *[sic]* is necessary is important.

Jim Jirjis: Seems that those writing the policy need to get input from infromaticians *[sic]* to ensure we get past high level reporting requirements to actually actionable and specific definitions

Meryl Bloomrosen: Patient ID Now, a coalition of more than 40 healthcare organizations, released a framework aimed at creating a national strategy around patient identification that protects individual safety and security. See: <https://catalog.ahima.org/view/251156390/>

Denise Chrysler: Regarding patient matching, HIPAA required a unique identifier for each patient but Congress has never funded.

Jim Jirjis: Clem Sorry for apologizing :)



steven: Also recommend reviewing the Health Vertiy platform for unique identification that protects names, etc

Heidi Fox: Need to clarify to stakeholders teh [sic] HIPAA public Health Exemption

Denise Love: so many resources are used to impute patient identity for purposes of statistical matching and it's wasteful. causes redundancy in data collection collecting the same data over and over.

Resources

[PHDS TF 2021 Webpage](#)

[PHDS TF 2021 – May 20, 2021 Meeting Agenda](#)

[PHDS TF 2021 – May 20, 2021 Meeting Slides](#)

[PHDS TF 2021 – May 20, 2021 Meeting Webpage](#)

[HITAC Calendar Webpage](#)

Adjournment

Janet and Carolyn thanked everyone for their participation and explained that they would take the TF member discussion points, comments, and results from the surveys into account when determining future TF work. Any further feedback can be submitted to the co-chairs.

The next PHDS TF 2021 meeting will be held on Thursday, May 27, 2021, from 10:30 a.m. to 12:00 p.m. E.T.

The meeting was adjourned at 11:53 a.m. E.T.