Health Information Technology Advisory Committee

Public Health Data Systems Task Force 2021 Virtual Meeting

Meeting Notes | May 27, 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 explained the processes by which information had been gathered from TF members. The co-chairs led a discussion based on a series of guiding questions related to public health surveillance and feedback submitted by TF members, all of which were included in the presentation materials. The TF reviewed a draft crosswalk document populated with information gathered by surveying TF members and from discussions held during previous meetings. There were no public comments submitted by phone, but there was a robust discussion in the chat feature in Adobe Connect and several comments and resources submitted via email.

Agenda

10:30 a.m.	Call to Order/Roll Call
10:35 a.m.	Opening Remarks
10:40 a.m.	Review Surveillance Discussion Guiding Questions and Draft Recommendations
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 10:30 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
Ngozi Ezike, Illinois Department of Public Health
Steve Hinrichs, Individual
Jim Jirjis, HCA Healthcare
John Kansky, Indiana Health Information Exchange
Bryant Karras, Washington State Department of Health

Steven Lane, Sutter 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
Aaron Miri, The University of Texas at Austin, Dell Medical School and UT Health Austin
Larry Mole, Veterans Health Administration
Abby Sears, OCHIN
Sheryl Turney, Anthem, Inc.

MEMBERS NOT IN ATTENDANCE
Claudia Grossmann, Patient-Centered Outcomes Research Institute

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

General Themes

TOPIC: OPENING REMARKS
The co-chairs opened the meeting, reviewed the agenda and PHDS TF charges, and explained the processes by which information had been gathered from TF members.

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. Feedback submitted thus far by TF members was included under relevant topic categories/questions.

TOPIC: DRAFT TF CROSSWALK DOCUMENT AND DISCUSSION
The co-chairs presented a 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.

Key Specific Points of Discussion

TOPIC: OPENING REMARKS
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.

Janet stated that the TF co-chairs appreciate feedback submitted in response to the surveillance question surveys. The discussion during the meeting would be centered around this feedback.

TOPIC: REVIEW SURVEILLANCE DISCUSSION GUIDING QUESTIONS AND DRAFT RECOMMENDATIONS

Carolyn explained that PHDS TF would hold a discussion based on the surveillance 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 in the next week. She directed TF members to examine the questions listed on slides #7 through #14 of the presentation materials.

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. Janet explained that the questions were centered around the following topics, and feedback gathered so far was detailed in the presentation materials, along with gaps identified:

- Data standards: For the key surveillance use cases (including but not limited to Testing, Case Reporting, Syndromic Surveillance, Immunization), what major gaps exist in health standards that prevent data from flowing between clinical and public health entities? What additional standards might need to be developed, further tested, or harmonized?
- Sharing, Use, Linking, and Integrating Data:
  - What real and/or perceived barriers exist that continue to inhibit progress in integrating multiple public health, social services, and clinical data sources while responding to public health emergencies?
  - What real and/or perceived barriers exist that continue to inhibit progress in integrating multiple public health, social services, and clinical data sources while responding to public health emergencies?
- Health equity and surveillance systems:
  - How do we ensure that surveillance systems adequately identify potential sources of bias and health inequity and address health equity?
  - What streamlined data sharing between social services and public health could enhance surveillance efforts and overall emergency response? What, if any, work would be needed to ensure accommodation of individuals' desire for and right of access to protected health information?
- Case Reporting: How can we reduce the manual public health reporting burdens for providers across the care continuum and support services? What steps and incentives are needed to scale automated methods of case reporting (i.e., electronic case reporting [eCR])?
- Laboratories/Electronic Laboratory Reporting (ELR):
  - During COVID-19, what were common themes encountered that impacted the timing and completeness of COVID-19 result data reported to state and local health departments?
  - What factors impact the timeliness of test reporting? How can the timing of reporting be improved?
  - What are common data quality or completeness issues encountered for COVID-19 lab data? How do these data quality issues impact public health response? What are some mechanisms for systematically avoiding and addressing these issues?

Janet asked PHDS TF members to consider the comments already submitted through the TF's surveys and a shared Google document when sharing comments during the meeting. Following the meeting, the co-chairs will work to refine and distill some of the comments, as Clem and others suggested that they were too diffuse.

DISCUSSION:

- Bryant Karras stated that he would send prepared comments related to ELR and challenges via the chat/email, as he would be required to leave the meeting early.
- Clem McDonald commented that the list of topics was too diffuse to make an impact. He raised the issue of the federal law against the use of patient identifiers, but he suggested that the TF discussed whether they could recommend taking advantage of Medicare's unique identifier or the insurance ID. He also discussed the lack of use/understanding of standards and stated that they should prioritize work on getting smaller public health departments to accept information electronically. He also raised the issue of miscommunications between public health and clinical care, which places a burden on physicians. Public health should not ask physicians to report information the referral labs can also provide. He stated that more dialog is needed here.
- Jim Jirjis submitted several comments, which included:
  - Call out the costs and maintenance needs for the point-to-point interface approach to communicate potential issues with them to stakeholders.
  - Lack of adherence to standards is linked to various differences in implementation. He suggested that the TF call out implementation guides (IGs).
  - Ensure that incentives include all stakeholders and not just a couple. He suggested adding public health, PPE suppliers, and others.
- Steve Eichner submitted several comments, which included:
  - Consider how information is being routed (and consider changing this process) and simplify the process to collect some data (like ask on order entry (AOE) questions) until after the laboratory result is provided. It reduces labs' storage resource needs.
  - Look at the rules of health information exchanges (HIEs) and the costs of onboarding and exchange. He differentiated between the costs associated with establishing the connection/connectivity (via VPN, web service, SFTP, etc.) and working to ensure that the message coming across that connection meets public health's quality standards.
  - Address race/ethnicity and disability issues with regard to health equity. Disability questions need to be expanded to collect more than just the question, "Are you disabled?"
- Arien Malec submitted several commented, which included:
  - Public health data systems would be run best when they build on a broader interoperability infrastructure and cautioned public health against adopting very specific/bespoke solutions. He discussed several newer/better approaches that led to improvements for public health, including improving the Orders/Results interface to allow clinicians to share this information bidirectionally and electronically.
  - Public health should be seen as healthcare; it is healthcare for populations.
  - Public health data infrastructure should be built on top of the interoperability used for individual care episodes.
- Abby Sears discussed issues OCHIN has identified with their patient population:
  - They have a higher rate of patients testing positive and a higher rate of needing to move patient data for contact tracing.
  - They have the highest rate of erroring out based on patient matching. The problem is that they have complete data, but they cannot match it effectively.
  - These issues are connected to health equity, and she emphasized the need for an algorithm. National frameworks need to be reinforced, and standards need to be supported and shared.
- Danielle Brooks voiced her agreement with Abby's comments and emphasized the need for greater consistency in capturing language data (beyond the demographic component), including communication information and patient privacy. Language access to facilitate public health messaging should also be considered.
- Steven Hinrichs emphasized the need for patient identifiers, especially for deduplicating COVID-19 test results received.

- Denise Love commented on her confusion around the pain points for capturing non-clinical data upstream.
- Clem stated that the TF should separate issues that can be solved through technical means and those that cannot. The TF cannot change the lack of a patient identifier, though it may choose to lobby for it. He stated that the lack of demographic data (race/ethnicity) goes deeper than standards; patients do not share this information for various reasons.
    - Janet responded that this information might be asked at one point in the patient encounter and then captured into the electronic health record (EHR), but she explained that the order placed in an electronic order interface does not always move the data over from the EHR. Therefore, the lab does not receive this information and cannot pass it on to public health.
    - Clem emphasized the need to investigate this issue and understand why it is happening.
    - Danielle stated that processes and best practices for asking for, capturing, and sending/receiving this data have been set up in inconsistent ways within and across health systems. Also, this issue is not necessarily a privacy concern, but she stated that the current race/ethnicity categories are insufficient. Also, she emphasized that more information is needed when explaining the need for this data to the patient.
- Jim Jirjis echoed Arien's comments about the need to build on a platform of interoperability and discussed his experiences with challenges around reporting on patient statuses from COVID-19 tests, which led to the creation of a "COVID Test Czar" position to properly track down results. He stated that these results were often shared in ways that were not machine-understandable, and the process was burdensome to the provider. Immediately available, standard-compliant information through an interoperable platform would reduce the burden on the provider and would make the data more readily shareable with public health.
- Les Lenert commented that the issue is not technical, but rather, it is a lack of incentives to align the systems. The TF should explore how to incentivize the healthcare system to provide ELR messages that are validated and accurate. The technology is in place, but incentives are not. He suggested a clinical-use-like data program for public health data contributions for providers report public health data as a positive incentive and a Medicare penalty program for providers who fail to fail to produce ELR messages that meet certification standards as a negative incentive.
- John Kansky suggested that the TF think about potential incentives and policies in a cross-cutting manner with issues raised earlier. He suggested that the TF examine the idea of setting a policy path toward having an HIE in every state and how this could lower the burden to implementation and tie into incentives. If the approach is to rely on national frameworks or a central federal government approach with each provider using the EHR and standards to report directly, this is very different than the use of HIEs. Perhaps a combination of the two would give providers the flexibility needed to achieve goals.
- Clem commented on point-to-point messages and stated that connecting each point independently creates an exponential workload. HIE's have been underemphasized as existing opportunities to make this work easier, and a lot of progress can be made by focusing on HIEs.
- Jim commented that because HCA did not have confirmation on what was received during the reporting process, their hospital was marked as submitting incomplete data. However, they found that the state was submitting incomplete data and their confusion around whether HCA or the state was the responsible party for submitting data to public health. He suggested that there should be a confirmation of receipt sent when data are submitted, and more insight is needed into what data might be lost when multiple intermediaries are involved.
- Steve Eichner stated that standards must support data that are necessary, and they must be communicated in an efficient and timely manner. He highlighted challenges encountered around creating data elements and incorporating information into HL7 messages during COVID-19 relief efforts. Also, he suggested that the routing of reporting could be improved to include more non-medical/demographic information. He discussed ways in which data reviews/checks could be pushed to the provider without creating too much additional burden.

- Abby discussed issues OCHIN encountered with matching algorithms, especially around naming/nomenclatures of culturally different demographics. Also, they encountered issues with states that required manual data entry, which reduced the ability to pull the data down into systems. There are challenges with data integrity and quality when manual reporting is used. Funding mechanisms and infrastructure modernization can solve some of the problems faced by public health, but the TF should also focus on incentivizing the efficient delivery of data with respect to requirements for manual entry.
- Steve Hinrichs stated that there are technical solutions that work and discussed recent work on algorithms that were developed to automatically identify case reports. He thanked Cerner and Epic for implementing these algorithms, which was impactful.
    - Clem asked for clarity around these algorithms and whether they could be used for patient matching. Steve responded that they were used for case reporting.
    - Carolyn and Janet stated that they would create questions to clarify these points as part of the homework for TF members.

Topic: Crosswalk

Carolyn explained that the co-chairs have accumulated information from the surveys/questions provided to PHDS TF members as homework, as well as from discussions held during meetings. It has been entered into a crosswalk document and was organized against the target areas identified by ONC. Suggested gaps, opportunities, and recommendations were identified. She displayed the draft document to the TF via the Adobe meeting client, and TF members were asked to review the document and be prepared to comment. The co-chairs will present the TF's preliminary recommendations to the HITAC at its June meeting, with final recommendations to be presented in July 2021.

Janet reviewed the various topic areas of the crosswalk, which were identified by ONC, and included surveillance, infrastructure, privacy and security, and research and innovation.

DISCUSSION:

- Jim Daniel highlighted the need to consider what makes sense for the recipients of the PHDS TF's recommendation and suggested making core recommendations based on the types of public health systems. He suggested that a template could be used to make these recommendations, which included:
    - Describe the ideal business case for what should be happening for public health data sharing: describe ideal data flows for systems from the perspectives of the various stakeholders. He stated that this would not include information about the standards.
    - Put other documented feedback into a template that addresses current standards, gaps, policy, and technical barriers. Then, the TF should address how to get to the ideal and which incentives apply.
    - This framework makes suggested changes clearer to the federal government.
- Aaron Miri echoed other TF members' comments. He also highlighted his personal experiences at UT-Austin with issues around processing labs and entering data from all of the various types of COVID-19 tests they received over the past year. He described challenges around processing labs in a timely manner and accommodating the variety in types of labs.
    - He suggested that the TF add an item on the crosswalk to address the need to accelerate lab results in the future. The focus should be on the speed of getting results and the speed of returning them to physicians.
    - He stated that there were also issues with associating labs to clinical notes, standards/lack thereof, and then sharing information across communities.
- Les suggested tasking ONC with looking at its existing framework and determining how to make use of the Trusted Exchange Framework and Common Agreement (TEFCA).

- Clem commented that the TF should focus on issues around home tests for COVID and related data. Also, the TF should study registration data that are not moving properly. Finally, public health and healthcare should be better merged in terms of their processes. Study money/funding can be used to analyze and address the main problem areas.
- Steven Lane encouraged the TF co-chairs to review the public chat from the current meeting.

Action Items and Next Steps

As their next steps, the PHDS TF 2021 were asked to review answers to the initial set of public health surveillance questions for discussion and a follow-up set of questions. Members who did not submit feedback were asked to complete the questions.

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

Brett explained that infrastructure discussion questions would be added to the TF's survey and that the link would be sent to TF members on Friday, May 28, 2021. They were asked to submit responses through Survey Monkey by Tuesday, June 1, by 10 a.m. EST. Carolyn explained that feedback from the TF surveys and spreadsheets would be shared on a weekly basis going forward. Brett added that the crosswalk document would be made available as a shared Google doc.

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. We will begin soon!

Steven Hinrichs: Mike, I need to ask about audio. Do I need to call the number to have audio connected. Steve

Mike Berry (ONC): @Steve - yes, the number for audio is in your calendar invite.

Steve Eichner: One challenge is that laboratories serve as "middle men" for data flow, requiring them to modify systems when additional data is needed. THis *[sic]* adds to implementation time and costs, as well as creates an opportunity for missing data.

Jim Jirjis: Jim Jirjis joined

Leslie Lenert: and that population healthcare is part of public health

Jim Jirjis: not seeing anything in chaty *[sic]*

Steve Eichner: Let's not forget equity issues regarding disabilities.

Jim Jirjis: And equity issues in funding for technical and process capabilitites *[sic]* in underserved areas

Steve Eichner: Currentlly, *[sic]* if disability informatioon *[sic]* is collected, it is VERY high level (e.g., are you disabled?)

Steven Lane: @SteveE - Labs are more than middlepeople. *[sic]* They should be treated as data sources for real time ad hoc queries by any stakeholder with a valid need - patients, providers, public health, payers, researchers, etc.

Arien Malec: The value set for race/ethniity *[sic]* requires the rigid OMB classifiers but *allows* the full CDC data set that is quite grandular.

Arien Malec: "granular"

Leslie Lenert: Is replicating the old style "case reporting yelow *[sic]* card" really what we want or do we want to enhance the ability for public health to easily and in an automated fashion investigate cases

Steven Lane: See https://www.healthit.gov/sites/default/files/page/2021-05/Standards_Bulletin_2021-2.pdf re Race and Ethnicity standards.

Leslie Lenert: eCR is a means to an end

Arien Malec: eCR is trigger based

Leslie Lenert: there are other means

Arien Malec: New triggers can be published.

Arien Malec: Not sure what the gap is here?

Leslie Lenert: trigger based automated case investigation is a better model

Steven Lane: eCR has also become very flexible with multiple technical and policy options - Direct, eHealth Exchange, Carequality, FHIR.

Arien Malec: https://www.cdc.gov/ecr/how-does-ecr-work.html

Arien Malec: It's a significant upgrade over the old style reportable conditions approach where there's a bespoke CDA for each condition.

Denise Chrysler: 09aq

Leslie Lenert: https://academic.oup.com/jamia/article/27/7/1136/5848746?login=true

Arien Malec: I'm pretty sure you described eCR Now :-)

Leslie Lenert: push the event to trigger investigation (a positive lab result). PULL the data, via FHIR to investigate the case and complete the eCR form

Arien Malec: But yes, exactly -- use triggers via CDS Hooks, Subscription & FHIR questionnaires to collect additional context,.

Leslie Lenert: when needed

Bryant Thomas Karras:
•Current surveillance and ELR system architecture was not designed for the volume of data and users. This resulted in slow performance that impacted the timeliness of public health action.
•Many labs had not onboarded to submit lab results electronically before the pandemic. Many lab reports were still being submitted to local health by fax and manually entered. With the dramatic increase in lab test

volume, manual entry was no longer feasible. Onboarding new labs to ELR takes significant time and staffing. Temporary solutions were needed to alleviate manual entry until labs were onboarded.
•Functionality to follow a case through the entire case investigation and contact tracing process didn't exist in a single system. Multiple systems were needed and interoperability between the applications was not standardized. Data transport and transformation between systems required significant manual work.
•The demands of the pandemic quickly outstripped the capacity of staff at the state and local level.

Clement McDonald: Jim Is Absolutely right !!!!

Aaron Miri: are public health entities considered covered entities or hybrid covered entities or other? That variation will cause a lot of "pause" in data sharing without clarity

Arien Malec: Typically no. Lemme dig up a massive twitter thread

Bryant Thomas Karras:
•The demands of the pandemic quickly outstripped the capacity of staff at the state and local level. There was a wide range of technical skill levels for individuals brought on for expanded case and contact investigation work. Learning new systems while working to conduct timely investigations was very challenging for many of our local partners.
•Informatics and data science capacity had not been adequately developed or funded pre-pandemic. A significant hiring effort was needed to build a workforce with the proper skillset to meet the need.
•Data needed to be collected for entities we hadn't previously received data from. Infrastructure had to be developed and implemented quickly to address the new needs. (Ex. Long term care facilities, adult family homes, schools, etc.)

Leslie Lenert: @Bryant has described the problem. eCR is part of a process to control infectious diseases that needs to combine several current systems in as automated and scalable a way as possible

Arien Malec: https://twitter.com/HealthPrivacy/status/1397238317419311107?s=20

Bryant Thomas Karras: see two chats... cut off 6 dot point total

Denise Chrysler: Ignore my prior chat. My cat walked across the keyboard when I was typing. HIPAA requires a unique patient identifier, but Congress never funded. I can check law to find requirment *[sic]* and to see if something changed since this was yaars *[sic]* ago.

Leslie Lenert: The idea of standardizing a way for public health to direct a question (a consult ?) to a clinician using FHIR, CDS Hooks, etc. for identified cases as part of investigations

Steven Lane: If we could get PH covered by HIPAA our world would tip on its axis, perhaps even only for part of what they do, e.g., case investigation, whch *[sic]* could be argued to fall under or be a natural extension of treatment and/or healthcare operations.

Aaron Miri: @Les - not every major EHR / CCHIT vendor is utilizing FHIR.

Leslie Lenert: @Aaron -- five years from now, should they?

Bryant Thomas Karras: have to drop now... sent via email to Janet and Mike Berry too

Aaron Miri: @Les - I personally believe its dissappointing *[sic]* that they aren't all doing so today. But so goes R&D cycles.

Aaron Miri: @Les - I did try. You can ask @SLane. He even tried to help. And we brought the CDC to the table. No dice

Denise Love: I don't know what's wrong with Adobe Connedct *[sic]* - Different systems like lab are designed for a specific function and we need to be mindful of loading reporting needs on a system not well-suited to capturing this. What are the best upstream sources for capturing SDOH and non-clinical data? and leveraging these upstream sources.

Jim Jirjis: here, here Arien!

Leslie Lenert: Technical solution: put a FHIR CDR in front of the EHR fed by V2.X

Aaron Miri: @Les - I even offered to construct it for "them" via one of the giant Cloud vendors..... still no dice

Leslie Lenert: this is the vendor? or a client?

Aaron Miri: vendor

Aaron Miri: EHR vendor

Leslie Lenert: Our job may not be to convince every vendor what is right. It is probably to describe what a rational future looks like and point to ways, as you have done, that the future can come at a reasonable cost and time frame

Denise Love: is the lab the best place to collect SDOH/language? I'm not clear how that would be feasible?

Steven Lane: Re Language, if improvements are needed, comments should be submitted here: https://www.healthit.gov/isa/uscdi-data/preferred-language

Denise Love: agree with Clem. It's not a standards issue as much as an operational one

Danielle Brooks: Agree with Denise

Aaron Miri: Dont forget - a lab order or result is only as good as the result. You need the note to be associated

Noam Arzt (HLN): One issue with race/ethnicity is coding, but another is the need for older systems to be able to capture (as well as communicate) MULTIPLE race/ethnicity designations which are a reality of many people's identities.

Aaron Miri: @Noam - Correct. Same with Gender

Steven Lane: Re "the standards are not there" for demographics, PLEASE submit comments so that ONC can continue to eveolve *[sic]* USCDI to address the gaps.

Steven Lane: Also, how about requiring Public Health to adhere to USCDI??

Aaron Miri: @Steven - Given the reliance on fax machines, that may be difficult :-/

Steven Lane: Difficult but still worthwhile. Both manual and eFax workflows will benefit from standardized data.

Abby Sears: I agree Steven

Aaron Miri: Wholeheartedly agreed Steven

Steven Lane: New public health funding should come with specific directives on what must be done and how the tools must be used. Too much independence breeds chaos.

Denise Love: agree with Les. Funding alone will not solve and HIPAA is not the major problem.

Steve Eichner: How would the incentive differ from the inclusion of public health reporting in Promoting Interoperability?

Leslie Lenert: @Lane: public health needs to be funded to adhere to USCDI but it would be a good start

Abby Sears: How do encourage the national framework?

Leslie Lenert: certify public health platforms and incentivize adoption

Deanne Kasim 2: Who would do certification of public health platforms? CDC? Need to appropriate funding for that for the long term (Congressional ask)

Jim Jirjis: Agree with Clem. Cannot have that many point to points

Steven Lane: Similarly Direct and eHealth Exchange hub can be utilized to avoid point-to-point connections.

Jim Jirjis: seems like it would be a waste to not tie this to the national framework that is already being developed

Leslie Lenert: @kansky and @mcdonald: state or regional HIE's are a critical piece of infrastructure that can help provide a GEOGRAPHICALLY BASEDS view of clinical events, help pre process data for public health. So important!!!

Steven Lane: Public Health is an identified stakeholder within TEFCA.

Jim Jirjis: Even the HIE's have their version of point to point technical and process variation

Jim Jirjis: we connect with 18 such HIEs. All different, and that is only 2 less point to point entitites *[sic]* for our 185 hosptials *[sic]* to connect with than the 20 public health departments

Leslie Lenert: @Jiris: but HIEs have a role as public health entities that bridge across health systems in collaboration with public health to provide that global picture of events in a state munincipality, , etcc. *[sic]*

Steven Lane: Is there value in encouraging/incentivizing adoption of eFax tools as a bridging strategy on the way to a FHIR-based future?

Jim Jirjis: WOuld *[sic]* love for the Public helaht *[sic]* solution to leverage TEFCA. Otherwise seems like we are reinvnting *[sic]* and maintaining a who other redundant wheel

Denise Love: Can front in edit protocols be applies at intake and rejected for resubmission?

Noam Arzt (HLN): While not related to labs but as an example of the last point, Immunization messages always have an HL7 v2 ACK so you know the message was received with or without errors.

Leslie Lenert: @Jiris: I think your right--public health needs to be hub in TEFCA and there needs to be a fair amount of push of data to create geographically based o composites data sets

Jim Jirjis: here, here, Les

Noam Arzt (HLN): A "hub" in TEFCA is a QHIN and I do not think PH agencies meet the criteria as they are emerging.

John Kansky: I think Jim, Les, and I should get a beer and talk about how the country might solve the challenges of HIE participation for multi-state providers. Some state's HIEs aren't very good... but many are. How can we (throguh *[sic]* policy, incetnives, *[sic]* etc.) make them *all* good?

Jim Jirjis: TEFCA needs to have the agility to respond to a national emergency including being able to rapidly identify data definitions and other requirments *[sic]* that need to be executed on a far tighter timeline than, for example, the current USCDI proposed timeline for adding new data elements

Clement McDonald: What was the mapping problem focused on . Patient matching?

Abby Sears: yes

Jim Jirjis: JOhn, we just did an analysis of all of the HIE's to which we connect and not onlyy is there tremendous technical variation and content variation, but each of these is an interface that has to be managed in a point-to-point manner over time. Add to that the public health reporting variation and it creates a lot of cost on the provider side. I guess it creates jobs...

Abby Sears: yes....there are issues about patient matching issues....especially hispanic names...

Leslie Lenert: So, maybe the standard we need on the public health side is ONE set of notifiable conditions for the country.

Steven Lane: Under TEFCA I believe that we will be able to have specialized QHINs. There has been talk of an HIE or consortium of HIEs applying to be a QHIN. Could such an entitiy *[sic]* serve as a specialized QHIN in support of Public Health entities nationwide?

Jim Jirjis: I would think public health departments would binteract *[sic]* with QHINS

Jim Jirjis: I like the idea of a specialized QHIN...only if there are inventives *[sic]* for the stakeholders to particpate! *[sic]*

Jim Jirjis: incentives

Noam Arzt (HLN): In the IZ domain we have the IZ Gateway positioning itself, in eCR we have AIMS/RCKMS. So we DO have some models for national facilitation of PH reporting.

Leslie Lenert: I think a public health QHIN would be very helpful as a way of organizing public health and providing a national view

Aaron Miri: @Les. Agreed. Something perhaps The Sequoia Project could look at and recommend as the RCE's a way to do this and possible funding sources?

Jim Jirjis: Spoke with Mariann yesterday on a call about this specifcally *[sic]*

Jim Jirjis: she had heard my comoments *[sic]* about leveraging TEFCA for the public health issue and her team reached out to set up a call.

Leslie Lenert: funding probably from CDC, ownership by the states and large municipal PH departments

Denise Love: Can any recommendations address broader PH information needs beyond surveillance/lab to be more holistic in our thinking? Much of the needed data come from non-traditional and other public data sources.

Aaron Miri: @Denise that's what i want to comment on :)

Leslie Lenert: Recommendation: ONC should develop an approach to use the TEFCA framework to address identified gaps in data provisioning to public health and evaluate the potential impact of a public health QHIN

Jim Jirjis: Les +1

Steven Lane: +1 Les

Jim Jirjis: I recommend reaching out to the Healthcare and Public Health Sector Coordinating council as they are trying to address this and have many consistuents *[sic]* as members that involve entities that control non-traditional data elements (PPE, etc.) Perhaps as an industry invite

Jim Jirjis: Mike Wargo would be point

Noam Arzt (HLN): One of the issues to address with a single PH QHIN is a single point of failure/scale. In NYC we are working hard (as is every IIS) to deal with unprecidented *[sic]* demand for services (data submission, query) and unprecidented *[sic]* assumptions about system performance and resilience. Even the smallest outage or delay gets a call from on high.

Jim Jirjis: I would start with making sure that there are no gaps missing. Even if it is one persons *[sic]* idea, just so we can get rationale for non-inclusion

Steven Hinrichs: Related to the topic of LOINC/SNOMED availability, the FDA SHIELD initiative has the ability to require standards (LOINC/SNOMED) in the package insert before the tests are marketed/sold

Jim Jirjis: For example Point to point challenges are not called out enough, implementation guides, record locator etc.

Leslie Lenert: @Noam: is embedding n public health departments in each in different QHIN feasible? Seems like the non-system we currently have

Jim Jirjis: We submitted a lot of infomration *[sic]* in the surveys. some seem to be missing from this

Jim Jirjis: document

Noam Arzt (HLN): @Les not sure. Was just commenting on TEFCA as it seems tobe *[sic]* emerging, not necessarily agreeing with its approach.

Steven Lane: Use of Survey Monkey has been a good add to the TF toolkit!

Clement McDonald: Think we should focus on fewer themes. Too many and very inter-twined as they stand now

Steven Lane: Also, I think I heard at the beginning that ONC will accept public comment via email. Is this a new opportunity??

Jim Jirjis: how do we do that , Clem without neglecting key components

Submitted on behalf of Steven Hinrichs:

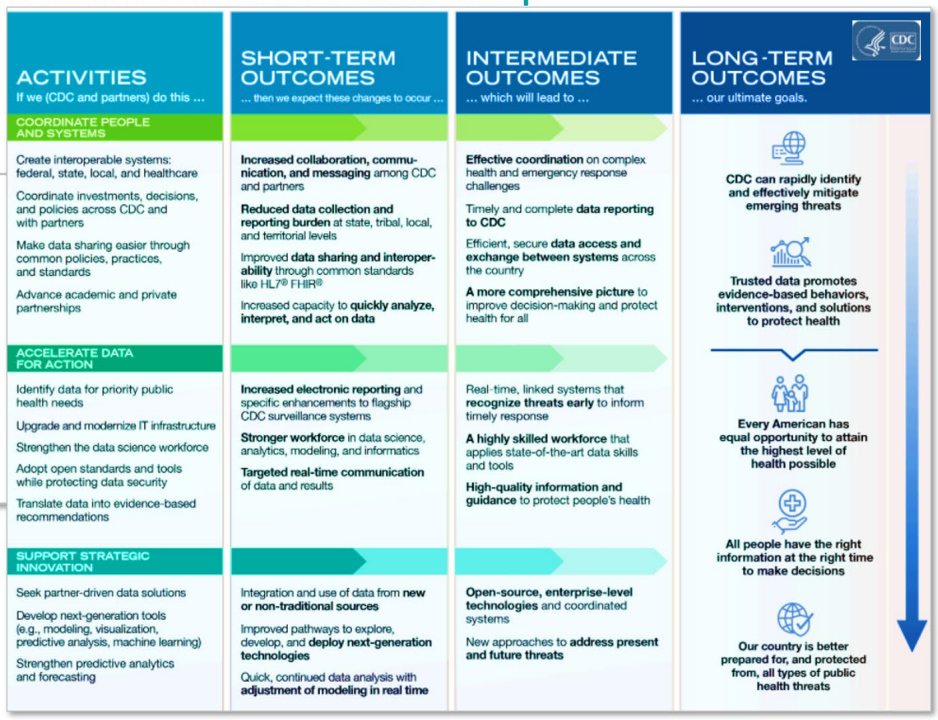
CDC Data Modernization Initiative Road Map

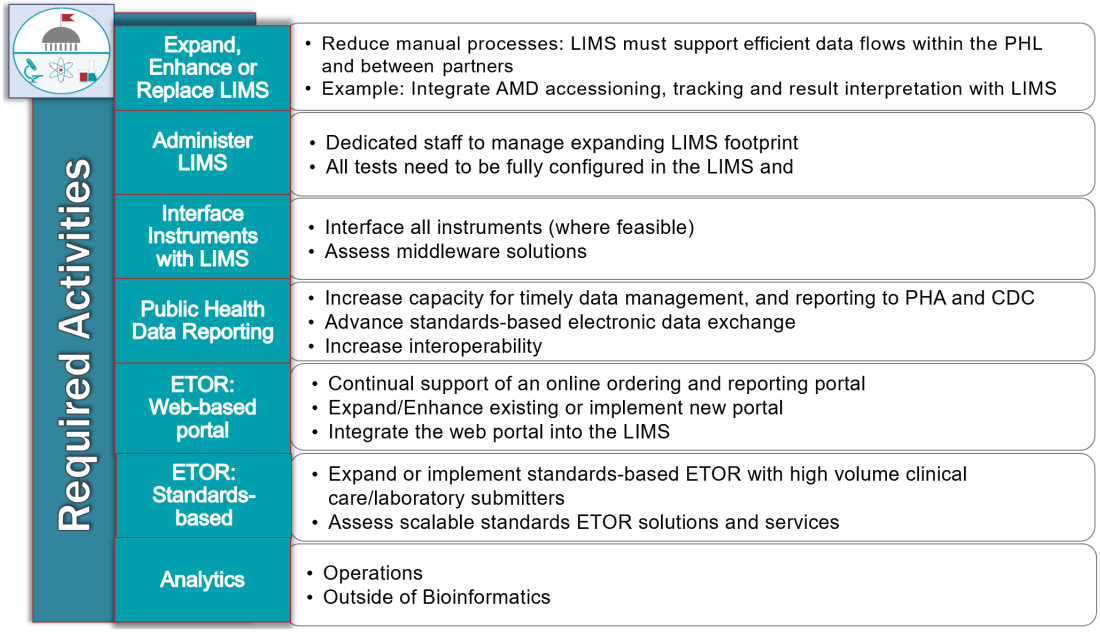
Improve timeliness and quality of data

Coordinate data activities and systems

Reduce burden on data partners

Effectively integrate emerging technologies





Advanced Molecular Detection (AMD)	Hosting solutions for Advanced Molecular Detection, such as WGS processing, pipeline management, and 3rd party integration
Antimicrobial Resistance Laboratory Network (ARLN) (Lab Web Portal + Reporting Portal)	Antimicrobial resistance reporting portal that accepts data from labs and makes it available for users
Electronic Case Reporting (eCR)	Electronic Initial Case Report sent from providers to state and local public health agencies and from jurisdiction to jurisdiction
Electronic Laboratory Reporting (ELR) – Cross Jurisdiction	Electronic lab reports sent from public health laboratories to state public health agencies
Emerging Infections Program (EIP)	Hosting, messaging, and data exchange solutions for state-based EI programs and state partners
Informatics Self-Assessment Tool	Tool for public health laboratories to assess strengths and gaps in informatics capability across 19 critical operational areas.
Lab Web Portal (LWP)	User portal allowing secure upload and download of validated data quickly in a variety of file types across a variety of diseases
Laboratory Information Management System Integration (LIMSi)	Enables public health labs to electronically send test results
Laboratory Information Management System (ELIMS)	CDC Electronic Laboratory Reporting data sent to state public health agencies
NNDSS Modernization Initiative (NMI)	Case notification message routing as part of CDC surveillance strategy and the NEDSS Modernization Initiative
OpenELIS	Hosting OpenELIS, a free open-source laboratory information system (LIS), for state public health labs, including SC
Public Health Immunization Data Exchange (PHIZ)	State public health immunization registries sharing information state to state
Public Health Laboratory Interoperability Project (PHLIP)	Influenza testing results sent from public health labs
Quest ELR	Onboard Quest facilities to AIMS for Electronic Laboratory Reporting to state public health agencies
Rabies Electronic Laboratory Reporting (ELR)	Animal Rabies surveillance project sending messages from public health laboratories
State and Territorial Exchange of Vital Events (Steve 2.0)	Application hosting for sharing of birth and death registry data
Vaccine Preventable Diseases (VPD)	Vaccine Preventable Diseases ELR messages sent from public health laboratories

QUESTIONS AND COMMENTS RECEIVED VIA EMAIL

The following comment was submitted by Joel R Greenspan MD MPH:

May 26, 2021

Janet Hamilton, Co-Chair
Carolyn Petersen, Co-Chair
Public Health Data Systems Task Force 2021/HITAC/ONC/DHHS

Dear Colleagues:

I am writing this note to share some personal perspectives and views on pertinent issues related to the deliberations of the ONC PHDS Task Force. Let me begin by thanking ONC, HITAC, and the PHDS Task Force for the openness of the task force process.

I have had an extensive multi-disciplinary career in public health as a medical epidemiologist with front-line and supervisory operational experience at federal (CDC) and STLT levels. Along the way I also gained considerable public health surveillance, emergency preparedness, and informatics skills.

Public health data systems (PHDS) challenges have long plagued the public health community. In the post-anthrax era, after-action reviews of complex high-consequence public health events have highlighted these ongoing problems. Unfortunately, the policies and technical infrastructures needed for effective, efficient, and coordinated response operations remain substantially unaddressed and the current emergency forced more "building the plane while flying" efforts. As Tom Frieden [1] pointed out ("Public health failed the COVID test.") at the HITAC meeting on May 13, COVID-19 has clearly highlighted serious ongoing data systems gaps at all levels of the public health enterprise. With a Presidential Executive Order [2] driving next-generation upgrades with long-overdue extra resources, updated policies, and modern technologies, a reformed national public health IT systems infrastructure should benefit the whole enterprise and especially STLT partners. We must get it right this time.

I have added a list of documents and video resources that have helped keep me informed of some of the important strategic issues associated with current PHDS challenges. Task Force members may find these resources useful.

Essential Elements of Information

Any discussion of public health data systems should ultimately arrive at a consensus about the essential elements of information required to manage a high consequence public health event. Having participated in the development of the first CDC Influenza Pandemic (H5N1) Operation Plan (OPLAN) in the mid-2000s, I reviewed an early version of the OPLAN from December 2006. At the time, much thought was given to the essential elements of information that CDC (and partners) would need to manage a pandemic. Noted in the plan:

"Information Management.

1) Purpose.

Broad, real-time, situation awareness is critical to successfully manage CDC's response to an influenza pandemic, inform higher level authorities and the general public, and support SLTT preparedness and response efforts. Situational awareness will be derived from timely access to analyzed information about illness and death; the availability, location, and utilization of critical resources throughout the U. S. public health and medical sectors (ESF #8); and details of key intervention activities that are directed at ill, exposed, or susceptible persons to slow transmission and minimize the influenza pandemic impact.

2) General Planning Guidance.

CDC will be required to support and coordinate multiple information gathering, analysis, and dissemination efforts, in collaboration with SLTT and international partners, during an influenza pandemic. Multiple streams of data, information, and intelligence concerning morbidity and mortality, resources, and interventions must be quickly and regularly assembled to maintain an accurate common operating picture that will inform decision-makers and guide the coordination of a comprehensive national response. The full spectrum of informatics support will be necessary to manage influenza pandemic operations.

3) Essential Elements of Information Include:

1. a) Early detection of human illness including case and cluster investigations (clinical, laboratory, risk factor) and timely documentation of pandemic spread and impact; characteristics of the circulating virus subtype.
2. b) Human and material resource availability (including surge capacity), location, and utilization.
3. c) Utilization and effectiveness of interventions including case management (isolation); contact management (contact tracing and quarantine); vaccination; antiviral medications; social distancing, and other non-medical countermeasures; analysis of vaccine and antiviral adverse events."

This remains a useful conceptual framework for what public health data systems should be able to support at scale and quickly in any high-consequence public health event at any level of the public heath enterprise.

Systems Thinking

In 2015 Bill Gates addressed the shortfalls of the international response to Ebola in West Africa in 2014-15 in an impressive 8 ½ minute TED Talk. [3] He notes, "The problem wasn't that there was a system that didn't work well enough. The problem was that we didn't have a system at all." He referred to key pieces of a coordinated response system as Surveillance and Data, Personnel and Equipment, and Treatments. These align with the 2006 CDC pandemic planning framework.

The Public Health Enterprise/Sector/Ecosystem

Literature references to the "public health enterprise" are not new, but the idea of a "collective effort to protect and promote the public's health" [4] and especially the advantage of addressing public health data systems challenges at the enterprise level are increasingly noted in the past few years. [4, 5, 6, 7] Michael Fraser [1] (ASTHO) made a strong appeal in this direction at his May 13 presentation. Enterprise informatics is a hallmark of business and industry who have increasingly transitioned to integrated/interoperable cloud-hosted enterprise informatics solutions. The public health enterprise responding to high-consequence public health events needs to highly automate and quickly collect, analyze, use, and share a spectrum of critical internally and externally generated preparedness and response data. This is also true for routine public health work. New systems should be able to support daily work in public health and adapt and scale as necessary in the event of emergencies. The enterprise can no longer afford to rely on multiple siloed data systems patched together. This causes inefficiencies in daily work and system breakdown in emergencies. "Enterprise-level information technology and data infrastructure that supports cloud-based platforms and real-time data automation" [6] should be considered for the next generation of public health information systems.

Myriad organizations and sectors are stakeholders of the public health enterprise and all play roles as sources or users of data in the overall ecosystem. It is important to recognize the roles of multiple organizations in a coordinated response to a high-consequence event and how they relate to, use, or provide critical data used in public health data systems. It is also important to note that local HDs are more alike than different in their necessary core capabilities and this part of the enterprise could greatly benefit from more standardization of core business processes that could be derived from a more enterprise informatics approach.

Public Health Surveillance

Public health surveillance (PHS) often means different things to different partners and can have a narrow or broad meaning depending on one's perspective. Its definition should be precise and well-defined and understood in the making of national PH policy. Most would agree that PHS represents a spectrum of processes [5] involving different organizations. PHS is not only collection of data (From whom and how should PH obtain critical data relevant to response operations?) but also use of data for PH decision making (What does PH do with the data it collects; at the population level; at the individual level?) and data and information sharing (How does PH share data and information with PH stakeholders?). These critical surveillance processes should all be considered in designing next generation, highly automated public health data systems.

Equity

Another aspect of equity in the current discussion should include the issue of very uneven structural alignment within the STLT public health enterprise. This equity issue is well described in the recent NAM discussion paper [7] and in the Lilly Kan [1] (NACCHO) presentation on May 13. There are many "have nots" in terms of resources and technologies across the spectrum of STLT organizations. I urge the TF to carefully consider the plight of STLT "have nots" in their recommendations for future investment and action. A new rising tide should lift all boats.

Thank you for your leadership in this important endeavor and wishing you success in your deliberations and recommendations.

Sincerely,

Joel R Greenspan MD MPH
Medical Epidemiologist
Atlanta, GA
greenspan@comcast.net
404-271-2240

References:

For TF members who may not be familiar with the responsibilities, structure, functions, and services of the current U.S. public health "system," its diverse governance and decentralized core entities, the inherent need for collaboration and cooperation in this enterprise, and the critical role of an efficient operational infrastructure, I recommend "United States Public Health 101," a useful slide deck from CDC (2013) (attached).

[1] ONC. Heath IT Advisory Committee Meeting. May 13, 2021. https://www.healthit.gov/hitac/events/health-it-advisory-committee-34

[2] The White House. January 2021. Executive Order on Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats. https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/21/executive-order-ensuring-a-data-driven-response-to-covid-19-and-future-high-consequence-public-health-threats/

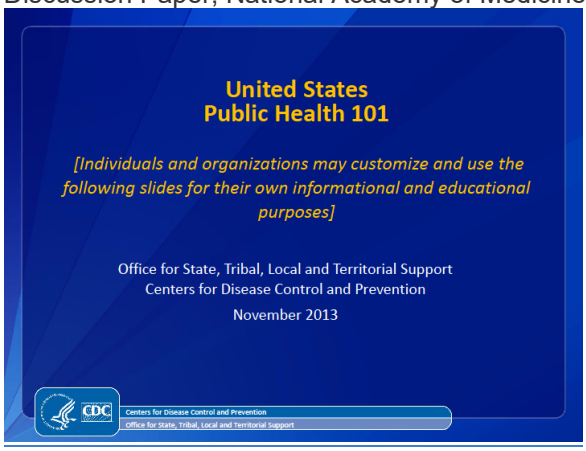
[3] Bill Gates. 2015. The Next Outbreak? We're Not Ready. TED Talk. https://www.youtube.com/watch?v=6Af6b_wyiwI&t=135s

[4] CSTE. 2019. Driving Public Health in the Fast Lane: The Urgent Need for a 21 st Century Data Superhighway. https://resources.cste.org/data-superhighway/mobile/index.html

[5] Jarris, Paul MD, MBA; Soper, Paula MS, MPH; Gordon, G. Scott PhD; Huang, Monica MPH; Rennick, Marcus MPH Shared Technology Infrastructure for the Public Health Enterprise, Journal of Public Health Management and Practice: May/June 2015 - Volume 21 - Issue 3 - p 308-309 doi: 10.1097/PHH.0000000000000259 https://journals.lww.com/jphmp/fulltext/2015/05000/Shared_Technology_Infrastructure_for_the_Public.12.aspx

[6] Lane, J. T. MPH; Smith, Karen MD, MPH; Allen, Meredith DrPH, MS; Surio, Priyanka MPH, PMP, CHES; Ruebush, Elizabeth MPH COVID-19 Highlights Critical Need for Public Health Data Modernization to Remain a Priority, Journal of Public Health Management and Practice: November/December 2020 - Volume 26 - Issue 6 - p 634-636. doi: 10.1097/PHH.0000000000001268. https://journals.lww.com/jphmp/Fulltext/2020/11000/COVID_19_Highlights_Critical_Need_for_Public.21.aspx

[7] DeSalvo, K., B. Hughes, M. Bassett, G. Benjamin, M. Fraser, S. Galea, N. Garcia, and J. Howard. 2021. Public Health COVID-19 Impact Assessment: Lessons Learned and Compelling Needs. *NAM Perspectives.* Discussion Paper, National Academy of Medicine, Washington, DC. https://doi.org/10.31478/202104c



The following comment was submitted by Meryl Bloomrosen, MBA, MBI, FAMIA:

Hi,

I hope that you are doing well. Kudos to ONC for convening the HITAC Public Health Data Systems (PHDS) Task Force and sincere congratulations to Janet and Carolyn for effective and efficient meetings!

Premier recently met with Micky Tripathi and identified areas of priority and confirm our willingness to continue to work with ONC. The issue areas we highlighted included data and interoperability between health care and public health as well as innovations for syndromic surveillance. To help inform the PHDS Task Force discussions and recommendations to the full HITAC, we wanted to share information with you (slides from prior ONC meetings are attached) about our efforts to leverage existing health information technology (EHRs) to enhance current (mostly ED focused) syndromic surveillance with real-time and upstream data collection (prior to testing, diagnosis, case reporting). Also wanted to provide links to some resources:

- Building A Real-Time Covid-19 Early-Warning System
- C. Menni, A. M. Valdes, M. B. Freidin, C. H. Sudre, L. H. Nguyen, D. A. Drew, S. Ganesh, T. Varsavsky, M. J. Cardoso, J. S. El-Sayed Moustafa, A. Visconti, P. Hysi, R. C. E. Bowyer, M. Mangino, M. Falchi, J. Wolf, S. Ourselin, A. T. Chan, C. J. Steves, T. D. Spector, Real-time tracking of self-reported symptoms to predict potential COVID-19. Nat. Med. 26, 1037–1040 (2020).

We would be happy to provide additional information or answer any questions. Have a great holiday weekend.
Thank you,
Meryl

Meryl Bloomrosen, MBA, MBI, FAMIA
Senior Director, Federal Affairs
Premier Inc
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Premier Discussion ONC April 9 2021_FI

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Resources

PHDS TF 2021 Webpage
PHDS TF 2021 – May 27, 2021 Meeting Agenda
PHDS TF 2021 – May 27, 2021 Meeting Slides

PHDS TF 2021 – May 27, 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 co-chairs shared the ongoing timeline and work plan for the PHDS TF 2021 and stated that the next TF meeting would be held on Thursday, June 3, 2021, from 10:30 a.m. to 12:00 p.m. E.T.

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