Meeting Notes

HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC)

May 13, 2021, 9:00 a.m. – 5:00 p.m. ET
VIRTUAL
EXECUTIVE SUMMARY

The co-chairs of the HITAC, Denise Webb and Aaron Miri, welcomed members, reviewed the meeting agenda, and the minutes from the April 15, 2021, HITAC meeting, which were approved by voice vote. Steve Posnack and Micky Tripathi welcomed members and shared remarks. The focus of this meeting was a public hearing on public health data systems. A series of presentations and panels were given on a variety of topics related to public health data systems, and HITAC members submitted questions and comments following each one. Arien Malec and David McCallie provided an update on the recent work of the Interoperability Standards Priorities (ISP) Task Force (TF) (ISP TF 2021). One public comment was submitted by phone during the two open public comment periods, and there was a robust discussion in the public meeting chat via Adobe.

AGENDA

09:00 a.m.      Call to Order/Roll Call
09:05 a.m.      Opening Remarks
09:15 a.m.      Remarks, Review of Agenda and Approval of April 15, 2021, Meeting Minutes
09:20 a.m.      Welcome Remarks
09:30 a.m.      Taking a Holistic Approach to Public Health Data Systems
09:55 a.m.      Public Health Systems Performance During COVID-19: Big Picture Perspectives
10:15 a.m.      Discussion
10:55 a.m.      Public Health Systems Performance During COVID-19: Operational Perspectives
11:20 a.m.      Discussion
11:50 a.m.      Public Comment Period
12:00 p.m.      Break
12:30 p.m.      Data Needs During High-Consequence Public Health Threats
12:50 p.m.      Discussion
01:30 p.m.      Technical and Infrastructure Issues: Current Status and Future Needs
02:00 p.m.      Discussion
02:30 p.m.      Legal and Policy Issues: Current Status and Future Needs
02:50 p.m.      Discussion
03:20 p.m.      Creating the Public Health Ecosystem of the Future
03:40 p.m.      Discussion
04:05 p.m.      Interoperability Standards Priorities (ISP) Task Force Update
04:45 p.m.      Public Comment Period
04:55 p.m.      Final Remarks and Adjourn

CALL TO ORDER/ ROLL CALL

Mike Berry, Designated Federal Officer, Office of the National Coordinator for Health IT (ONC), called the May 13, 2021, meeting to order at 9:00 a.m.

ROLL CALL

Aaron Miri, The University of Texas at Austin, Dell Medical School and UT Health Austin, Co-Chair
Denise Webb, Indiana Hemophilia and Thrombosis Center, Co-Chair
Michael Adcock, Magnolia Health
Cynthia A. Fisher, PatientRightsAdvocate.org
Lisa Frey, St. Elizabeth Healthcare
Valerie Grey, New York eHealth Collaborative
Steven Hester, Norton Healthcare
Jim Jirjis, HCA Healthcare
John Kansky, Indiana Health Information Exchange
Kensaku Kawamoto, University of Utah Health
Steven Lane, Sutter Health
Leslie Lenert, Medical University of South Carolina
Arien Malec, Change Healthcare
Clem McDonald, National Library of Medicine
Brett Oliver, Baptist Health
Terrence O’Malley, Individual
Carolyn Petersen, Individual
Raj Ratwani, MedStar Health
Abby Sears, OCHIN
Alexis Snyder, Individual
Sasha TerMaat, Epic
Andrew Truscott, Accenture
Sheryl Turney, Anthem, Inc.
Robert Wah, Individual

MEMBERS NOT IN ATTENDANCE
Adi V. Gundlapalli, Centers for Disease Control and Prevention (CDC)
James Pantelas, Individual

FEDERAL REPRESENTATIVES
James Ellzy, Defense Health Agency, Department of Defense
Ram Iyer, Food and Drug Administration (FDA)
Jonathan Nebeker, Department of Veterans Health Affairs
Michelle Schreiber, Centers for Medicare and Medicaid Services
Ram Sriram, National Institute of Standards and Technology

ONC STAFF
Micky Tripathi, National Coordinator for Health Information Technology
Steve Posnack, Deputy National Coordinator for Health Information Technology
Elise Sweeney Anthony, Executive Director, Office of Policy
Avinash Shanbhag, Acting Executive Director, Office of Technology
Mike Berry, Designated Federal Officer

PRESENTERS
Daniel Jernigan, Acting Deputy Director for Public Health Science and Surveillance, CDC
Tom Frieden, President and CEO, Resolve to Save Lives
Mark McClellan, Duke-Robert J. Margolis Center for Health Policy
Greg Singleton, Health and Human Services (HHS) Office of the Chief Information Officer
Michael Fraser, Association of State and Territorial Health Officials (ASTHO)
Linda Rae Murray, University of Illinois School of Public Health
Anne Zink, Alaska Department of Health and Social Services
Ian Williams, CDC
Sarah Boateng, HHS
Lilly Kan, National Association of County & City Health Officials (NACCHO)
Linda Thomas-Hemak, The Wright Center for Community Health and its affiliated entity, The Wright Center for Graduate Medical Education
Joseph Kanter, Louisiana Department of Health
Jonathan Greene, Office of the Assistant Secretary for Preparedness and Response (ASPR), HHS
Sam Imbrie, Office of the Assistant Secretary for Preparedness and Response (ASPR), HHS
Annie Fine, New York City Department of Health and Mental Hygiene
Terra Abrams Ankrah, District of Columbia Department of Health
Karen DeSalvo, Google Health
Hans Buitendijk, HIMSS Electronic Health Record Association (EHRA) & Cerner Corporation
Mary Beth Kurilo, American Immunization Registry Association
James Watt, California Department of Public Health
OPENING REMARKS

Steve Posnack welcomed everyone to the May 13, 2021, virtual meeting of the HITAC and briefly reviewed the agenda. He welcomed Ram Iyer, the new Federal representative from the Food and Drug Administration (FDA). Ram introduced himself and noted that he would be replacing Dr. Amy Abernethy.

Steve explained that ONC had just kicked off a new effort called Health Interoperability Outcomes 2030 and referred HITAC members to the ONC Buzz Blog post on the topic. ONC hopes to publish a prioritized set of interoperability outcomes that would or should be possible by 2030 and has launched a call for brief supporting statements as part of the process, which will run from May 13 through July 30, 2021. The HITAC will be given an opportunity to provide input on the 2030 outcomes at its June 9, 2021, meeting.

Steve welcomed the HITAC co-chairs, Denise Webb and Aaron Miri, and all of the presenters.

REMARKS, REVIEW OF AGENDA, AND APPROVAL OF APRIL 15, 2021, MEETING MINUTES

Aaron Miri and Denise Webb, HITAC co-chairs, welcomed members and thanked everyone who helped put the meeting together in advance. Aaron reviewed the agenda and list of planned panels and presentations. Denise reminded attendees that there would be two open public comment periods.

Aaron invited members to examine the minutes from the April 15, 2021, meeting of the HITAC. Members of the HITAC submitted no comments or corrections. Aaron called for a motion to approve the minutes, which was made. Andy Truscott seconded the motion.

The HITAC approved the April 15, 2021, meeting minutes by voice vote. No members opposed, and no members abstained.

WELCOME REMARKS

Micky Tripathi, the National Coordinator for Health IT, welcomed everyone to the May 13, 2021, virtual meeting and hearing of the HITAC. Micky explained that ONC and the Centers for Disease Control and Prevention (CDC) are co-leading work related to an executive order on how public health data systems aid in public health emergencies. He discussed the importance of interoperability and transparency in future work on public health data systems. He noted that the lack of a single public health system in the U.S. and a patchy infrastructure was proven to be not as responsive as it should have been during COVID-19 pandemic relief efforts regarding data accuracy, timeliness, reliability, and relevance. Public health experts have long identified the resulting gaps, but public health systems have historically been underfunded. He stated that there is an opportunity to build more vital public health systems, so they must use the funding and urgency to get past the current crisis and prepare for the future. He suggested that thinking in terms of a public health ecosystem would be more helpful. He thanked everyone for their attendance, testimonies, and presentations in advance.
Dr. Dan Jernigan thanked everyone for their engagement and stated that it is important to the CDC to have their input, information, data, guidance, and recommendations as they move forward with their Data Modernization Initiative (DMI). The DMI now has the funding and momentum that it previously lacked, so now the CDC would like to gather information for short-term needs (pandemic relief efforts, etc.) and also to prepare a long-lasting, sustainable approach to improve public health data systems. He discussed his previous work as a board member of HL7, noting that many items they identified at the time never changed, but the pandemic proved that there was an immediate need to address the issues. In response to a question from Aaron, Dan discussed work he and Micky have done recently to establish a list of next steps, including planned hackathons in summer 2021 to look at Fast Healthcare Interoperability Resources (FHIR) and the usefulness of FHIR-based standards for getting public health information from electronic health records (EHRs). Micky added that they have considered FHIR accelerator activities that are focused on public health, too.

Aaron asked Micky to comment on the future of the U.S. Core Data for Interoperability (USCDI) and other standards-based work in terms of a focus on public health, social determinants of health data (SDOH), and mental health. Micky responded that they are looking at the USCDI for opportunities to move the industry forward, and public health is the most important need and part of the solution. ONC, CMS, and the FDA should work together to use all levers to move this work forward, to support SDOH and FHIR accelerators, and to get data standardized so it will be more useful for future public health initiatives.

Micky explained that the overarching charge of the new task force will be to inform HHS’s response to President Biden’s The Executive Order on Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats, the HITAC-led Public Health Data Systems Task Force (PHDS TF) had its kick-off meeting in early May 2021. Micky thanked Carolyn Petersen and Janet Hamilton for co-chairing the PHDS TF. He stated that the specific charge is that the Public Health Data Systems 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, long-term service and support systems, research and innovation, and empowering individuals.
- Identify characteristics of an optimal future state for information systems relevant to public health and their use.

Micky emphasized the importance of this work and directed HITAC members to the presentation materials for the PHDS TF’s meeting schedule and addition information.

A video of the Public Health Hearing HITAC meeting presentations and discussion periods is available on the main webpage for the May 13, 2021, HITAC meeting, along with meeting materials, presentation and testimony slide decks, and a meeting transcript. Presenter biographies were also shared on the webpage.

Aaron encouraged HITAC members to email questions and comments on presentations and testimony to Mike Berry following the meeting.

**PRESENTATION: TAKING A HOLISTIC APPROACH TO PUBLIC HEALTH DATA SYSTEMS**

Discussion:

- **Les Lenert** thanked the presenter for bringing up the importance of informatics at the CDC and moving forward with collaborations in an ecosystem. However, he noted that this reflects a large culture change for public health and discussed ways in which culture has trumped strategies. He asked how the culture of the CDC can be changed so that it is ready to work within the information ecosystem instead of within the concept of supply chains.
  - **Tom** responded that behavior has to change the culture and suggested that work has to be done to reenvision how informatics is designed and implemented. Currently, doing informatics work in public health is cumbersome due to cobbled together systems. He directed HITAC members to review the product that his group, Resolve to Save Lives, created in response to COVID-19 called Simple. [www.simple.org](http://www.simple.org) It allows patients to quickly connect with healthcare workers to manage treatment programs, but he explained that it had deployment issues in the U.S. due to issues with the informatics environment. The product was designed in an agile, user-centric way, but it ran into issues with cumbersome systems.
  - **Les** responded that standards are needed to back interoperability and discussed how standards could be created and reengineered. He asked if the CDC believes that it should focus on informatics at a national level to raise the tide for all levels of public health (state, local, tribal, territorial) to create a common platform.
  - **Tom** responded that informatics has to be integrated and must serve needs. He described work done previously in which functionality and usefulness were not the primary concern.

- **Clem** voiced his agreement with **Tom’s** comments about issues caused by budget separation for various diseases at the CDC. He highlighted issues with public health being unable to take in data from labs during the pandemic, even though it was standardized, and the messaging done by the CDC around the spread of COVID-19.
  - **Tom** responded that, regarding changes in the CDC’s messaging, the essence of an effective response is to learn during the response and to adjust/adapt. There is still a lot of epidemiology that lacks information because of issues with information systems. He disagreed that laboratories were sending fully standardized information during the pandemic; the CDC saw many problems. A feedback loop for learning is needed.

- **John Kansky** responded to **Tom’s** call for a government option to create a public health information network and discussed his experiences with health information exchanges (HIEs) and their roles. He asked if the government would consider contracting with them in states where the HIE is robust and capable.
  - **Tom** congratulated John for the Indiana HIE’s work and responded positively to his suggestion, noting that more work on examining standards, functionality, and implementation would need to be done first to ensure interoperability. He suggested that a public option that is forced to function effectively would outcompete the private section. The goal is to improve health, not let contractors make money. He described several potential scenarios.

- In closing, **Tom** thanked the HITAC for the opportunity to present and asked HITAC members to consider the following points:
  - What can be built that's a truly public good?
  - How can you get the functionalities that you need right?
  - How can you do it in a way so that it’s easier and more pleasant and engaging and effective to use than what exists or what’s being sold today?
PANEL: PUBLIC HEALTH SYSTEMS PERFORMANCE DURING COVID-19: BIG PICTURE PERSPECTIVES


Greg Singleton, MS, Senior Advisor for National Security and Advanced Research, Health and Human Services (HHS) Office of the Chief Information Officer, introduced himself and presented testimony on the HHS Protect Public Data Hub platform and its role in the COVID-19 response.

Michael Fraser, PhD, MS, CEO, Association of State and Territorial Health Officials (ASTHO), introduced himself and presented testimony on ASTHO’s recent work, experiences, and suggestions based on findings from its participation in COVID-19 responses efforts.


Anne Zink, MD, FACEP, Chief Medical Officer for the State of Alaska, introduced herself and presented testimony on her experiences with public health systems during the COVID-19 pandemic as a practicing emergency physician and President-Elect of ASTHO. She asked the HITAC to focus its efforts on several key areas.

Discussion:

- Arien Malec thanked the presenters. He stated that there are all of the standards necessary for capturing and sharing race/ethnicity demographic data but noted that race is often not specified in records for vaccine recipients. The issue stems from not using the existing standard, so data is not flowing between the hospital, labs, and public health. He suggested that hospitals and labs are incented to get the data for reimbursement but that it does not flow to public health. He inquired about incentives to break down strict programmatic and siloed requirements around public health, and asked to consider the funding mechanisms and incentives to address systems problems.
  - Linda Rae Murray responded that race/ethnicity categories are racist political and social constructs and stated that constant conversations need to be held around how people are identified. She voiced her support for Tom Frieden’s comments and noted the practice of withholding payment as a method for forcing certain pieces of information from the public for the purposes of public health work.
  - Anne Zink voiced her support for Linda Rae’s comments and suggested looking beyond public health funding sources to Medicaid and Medicare. There could be a cost charged to hospitals, labs, or systems that do not report race/ethnicity data and syndromic surveillance because the lack of that data is costly for public health, IT, and Medicaid/Medicare spending.
  - Mark McClellan highlighted issues related to trust as a reason why people do not share race/ethnicity data when they get vaccinated. Linking collection to payments and strategies to address health equity issues will increase participation rates.
Clem McDonald asked Greg Singleton to elaborate on the system he described, including information on who runs it, as it could be a solution to issues described by the other panelists.

- Greg responded that federal systems were not initially in place at the outset of the pandemic or were not configured/capable of addressing issues. He described work done to get systems in place and running, including the HHS Protect Public Data Hub platform, and highlighted remaining challenges. He asked for feedback on how the work can pivot and evolve beyond the current focus on COVID-19 relief efforts. Also, recognized that political problems play a role, in addition to technical issues.

- Mark McClellan responded that the panelists were describing a current state, not necessarily complaining, and noted that they have learned many lessons during the pandemic that would transfer. However, systems developed during this time should be examined to determine if they are using best practices for public health work going forward. There are challenges remaining, but there are also bright spots in the work that has been done.

- Clem commented on his personal experiences at a hospital in Indianapolis where there were challenges around capturing race/ethnicity data and asked for feedback from the panelists on why that might have happened.

- Linda Rae Murray discussed, in response, her own experiences where this data were often not captured and suggested that how the data categories are divided and the questions are asked are strange. People often give more coherent answers to a person who is asking respectfully than a computer. Allowing people to self-identify and working to help new immigrants understand the role race plays in the U.S. is helpful. Training is needed for clerical staff, physicians, nurses, and the entire system.

- Anne Zink added to Linda Rae’s comments, agreeing that more training is needed upstream, and stated that the questions people are asked could be reworked to allow people to self-identify and feel more comfortable. She stated that work also needs to be done on systems and described Alaska’s issues with missing race/ethnicity data for vaccinations.

- Mike Fraser echoed the others’ statements that patients do not trust the healthcare system and often assume that their race will lead to substandard care. The legacy of racism in healthcare needs to be unpacked, and messaging to patients can be improved.

- Clem summarized the others’ comments that the issue is multifaceted, and incenting will not solve it.

- Aaron thanked those who submitted comments and noted his personal experiences in Texas overlapped with Dr. Zink’s in Alaska. He emphasized the critical nature of partnering with people and treating people as humans and not as a data standard.

PANEL: PUBLIC HEALTH SYSTEMS PERFORMANCE DURING COVID-19: OPERATIONAL PERSPECTIVES

Ian Williams, PhD, MS, Deputy Director of the Center of Preparedness and Response, CDC, introduced himself and presented testimony on his experiences working on the early response to the COVID-19 pandemic. He discussed how public health systems did or did not perform to inform the larger federal response at an operational level and highlighted opportunities for improvement.

Sarah Boateng, MHA, Chief of Staff, Office of the Assistant Secretary for Health (OASH), HHS Office of the Secretary, introduced herself and presented testimony on her experiences working on COVID-19 response efforts, previously at the Pennsylvania Department of Health, and currently at OASH. She
highlighted several operational challenges and opportunities related to data-driven public health responses.


**Jim Jirjis**, MD, MBA, Vice President and Chief Health Information Officer, HCA Healthcare, introduced himself and presented testimony on his perspective on public health reporting during the COVID-19 pandemic and more broadly. He highlighted several challenges and opportunities connected to conducting public health reporting. View his presentation here: [https://www.healthit.gov/sites/default/files/facas/2021-05-13_Jim_Jirjis_Presentation.pdf](https://www.healthit.gov/sites/default/files/facas/2021-05-13_Jim_Jirjis_Presentation.pdf)


**Discussion:**

- **Aaron Miri** asked **Linda Thomas-Hemak** about her suggestions to gather information about public goodwill from social media or other less commonly used data sets. He asked if these methods could be standardized and incorporated into electronic medical records (EMRs) in the future to facilitate the exchange of this data. How could this work?
  - Linda responded that this capacity is absent in the current system, so it would have to be done centrally. People would have to be allowed to tell their own stories instead of metrics that they do not understand being imposed on them.
  - Aaron shared an anecdotal story about using social media during the early days of vaccine hubs to improve their process/operational workflows and help people navigate the system.

- **Aaron** asked **Lilly Kan** to comment on whether standardized codes used in EMRs, like ICD-10, should be accelerated for use in systems, even if they are pending official certification by the World Health Organization (WHO). He stated that vendors took over a month to adopt a code during the early days of the COVID-19 pandemic.
  - Lilly responded that addressing the solutions and approaches to modernization that support interoperability between the public health, healthcare systems, and the other systems looks very different across different local health departments. There is a need to consider the size and capabilities of local health departments and the jurisdictions they serve, and they need to be engaged in the process.

- **Clem McDonald** suggested that work could be done faster and referenced the quick turnaround time on the recent collaboration between the CDC and FDA. He acknowledged that this work is harder on a national level and suggested using a temporary code.
Aaron commended the CDC for its work around electronic case reporting (eCR) and partnering with other organizations while recognizing HITAC member Steven Lane for his contributions. Aaron asked Ian Williams if there are better ways for the provider and overall communities to engage the CDC to move away from fax machines and toward eCR?

- Ian responded that if future work uses COVID-19 efforts as a model, further innovation will be needed due to the rushed circumstances of the original work. The pandemic is ongoing, so there are continuing opportunities to build a better basis of work.
- Linda stated that it can be difficult to trace and report adverse events due to the current patchwork of reporting systems. Getting primary care to do this exhausts the workforce and diminishes reporting capacity and the long-term ability to evaluate causality. This lack of infrastructure erodes provider and patient trust, and this is a reason for vaccine hesitancy.

Sheryl Turney asked the panelists to discuss their highest priority initiatives. Also, she discussed issues with EMR systems have not provided the proper places for COVID testing and vaccine information to be entered across multiple instances of care. She described her personal experiences sharing vaccine and insurance information with the payer. There are gaps in the current system, and she asked how they should be addressed.

- Jim Jirjis suggested that providers could incentivize everyone to enter information in the same way, nationally, via an intermediary, technology, or other solutions, instead of different public health departments having different requirements.
- Linda responded that this is the time to work on increasing our ability to track and collect accurate, complete demographic data because new and better IT tools will be built as a result of the pandemic. Building out fields to capture more/multiple-race data, sexual orientation and gender identity (SOGI) data will allow for policy decisions to be made in the future.
- Lilly voiced her agreement with Linda’s comments, noting that challenges and conversations occurring around adult immunizations now might provide solutions to other issues with systems (data capture, connects). There is a huge opportunity to leverage the current momentum around health IT, healthcare data, immunizations, and stakeholders.
- Linda emphasized the provider’s need for information to effectively do the job, do the right thing for patients and families, make it visible/real-time, engage all stakeholders in getting data to flow, put out sanctions for information blocking, and do not allow the people between the government and provider community to modify metrics and change rules of engagement.
- Aaron responded that his medical staff often shares the same comments.

Clem commented on the heavy time burden on providers whenever they are required to capture more data and suggested that labs can also share this information.

Micky Tripathi asked the presenters to elaborate on what kind of actionable and informative information they would like to get back from provider organizations.

- Linda described examples of situations in which necessary vaccine information is missing during a primary care encounter or patients do not retain vaccine information and then suffer potentially related adverse events. She stated that her burden to go back to trace and report adverse events is painful and cautioned that others might not complete the same steps. She discussed workarounds for absences in data and how they affect outcomes and decision-making.
o Jim echoed Linda's comments that too often, clinical staff and physicians must make care decisions with incomplete information, which is dangerous or spend time trying to get the information. The flow of information would alleviate this burden. He described challenges HCA faced in managing resources and knowing who to contact to share information with the public when trying to respond to the pandemic. He suggested that a federal system would have allowed for greater collaboration to make resource decisions. Though HCA eventually built necessary tools, they were not able to collaborate outside their organization. He explained that these solutions would also be useful in the event of a hurricane.

o Clem emphasized Jim’s comments and asked when TEFCA would be running, suggested that it would accelerate the information flows without a lot of work. This would result in better care and less wasted time chasing data.

o Linda suggested that they look at the language challenge in the Meaningful Use campaign to determine if functionality is not there for daily practices.

o Clem highlighted a disconnect between ONC and labs in terms of sharing results with codes.

- Arien Malec summarized the previous comments on the presentation and stated that standards exist for race/ethnicity. The issue is that systems have not been connected to use the available standards. He emphasized the need to source normalize data and flow through interoperability mechanisms to make information available. There is a need to look at the incentives and information flows that allow standards to be used. He emphasized that if flows are not connected, the burden increases, instead of decreasing, because people are forced to do manual workarounds. He thanked the presenters.

- Jim voiced his agreement and described The Sequoia Project’s approach of using a forum to gain consensus around the process and interpretations.

- Linda voiced her support for accelerating and learning from accomplishments and referenced the examples of E-Prescribing and the PDMP. She suggested that there is an untapped capacity for providers, patients, families, and social media to accelerate change.

- Aaron recognized the provider community for their efforts to overcome challenges to care for their patients.

BREAK

Aaron reminded attendees to follow commentary around the meeting on social media using the hashtag #HITAC. Following the morning presentations, the meeting was opened up for the first of two public comment periods. Then, the HITAC took a short break for lunch.

Mike Berry reconvened the meeting at 12:30 p.m., and Aaron welcomed HITAC members, presenters, and the public back to the meeting while thanking the morning’s presenters and providing a brief overview of the afternoon panels and presentations.

DATA NEEDS DURING HIGH-CONSEQUENCE PUBLIC HEALTH THREATS

Jonathan Greene, Deputy Assistant Secretary and Director, Office of the Assistant Secretary for Preparedness and Response (ASPR), HHS, introduced himself and presented on the topics of how ASPR leverages data from its COVID-19 response activities and how ASPR is taking lessons learned from the COVID-19 to be better prepared for future responses.

Sam Imbriale, MPH, Director, Information Management Division (IMD), Office of Security, Intelligence & Information Management (SIIM), HHS, introduced himself and provided testimony on his experiences with federal data collection/analysis and data infrastructure needs during the COVID-19 pandemic.


Discussion:

- Les Lenert asked the presenters to comment on how far public health got in terms of predicting where the pandemic was going next in the U.S. He inquired about linking that to both enhancing the commercial supply chain and dispensing resources from the stockpile? Was the U.S. really only able to get two weeks in front?
  - Sam Imbriale responded that it depended on the geographical area and early data collection; some areas had more robust reporting from state and local government, healthcare systems, and testing data coming from the CDC. His agency got close to 100% reporting, including commercial supply and distributor data for the top personal protective equipment (PPE) categories, by early fall of 2020.
  - Jonathan Greene stated that information from state and local collection (health departments, health systems) requires context and discussed the example of health facilities reporting low PPE inventory when there was really enough supply in the chain. Confusion was due to facilities having preferences for specific types of PPE. Also, he suggested that there is a need to be more transparent about what is in the national stockpile and its purpose, which is not to take the place of the supply chain. Better visibility along the supply chain will allow for shortages to be identified, and assets from the national stockpile can then be used to build a temporary bridge. He suggested that they need to encourage and ensure ongoing collaboration and cooperation in data sharing and transparency in the supply chain.
  - Joseph Kanter described the state perspective based on his experiences in the early days of the pandemic in Louisiana. He stated that they were trying to predict what would happen following the employment of mitigation measures, like setting up large field hospitals, but added that they often had mitigation/prediction issues. These got better as the pandemic continued.
- **Jonathan** stated that compliance is a wildcard and suggested that a separate conversion should be held on how to deal with misinformation spread through social media and alternate sources of information. He was surprised by how often scientifically based guidance was ignored or overlooked. That should be part of the mitigation strategy going forward.

- **Les** commented that systems that are working well at a federal level should be made available to state and local governments. Do not allocate according to population size; allocate according to need. That requires more locally available modeling infrastructure.

- **Aaron** added that forecasting requires case data and information about what is happening in communities. Getting information to flow properly requires the cooperation of all systems, including material systems, contact data, materials management data, EHR data, and more.

- **Aaron** asked **Terra** how to account for the communities that are particularly rural and are not using electronic systems/are using paper and that are undercounting, from a vital statistics and records perspective. He asked how they might extrapolate and expand electronically to get those records digital and then be able to react faster during a public health emergency.

  - **Terra** responded that the District of Columbia was using paper death records for events that occurred outside of their electronic death registration system until 2018, with they made it mandatory that all records be entered into the electronic system closer to the date of the event by working with funeral directors, medical examiners, and hospitals, allowing them to respond faster. She suggested that all states adopt laws requiring their providers to participate in electronic registration of vital events so that the state’s staff can drive registrations faster.

- **Aaron** responded with interest and discussed an opioid syndromic surveillance platform Texas built.

- **Aaron** asked **Sam** to comment if there is a playbook to demonstrate how to model, visualize, and develop that common language for public health efforts to communicate with the public health authority, fostering public trust.

  - **Sam** responded that work has been done to share best practices, methodologies, codes for models through HHS Protect and the COVID data tracker. They have relied on the CDC to be the trusted source of public health data and public health modeling; they would continue to leverage the CDC’s resources. However, there is no one-stop-shop for these practices and methodologies. Leveraging the executive order to put methodologies and the source codes around how they arrived at those models would allow other entities to do the modeling themselves and check their work. A centralized repository/location for modeling best practices, source codes, and methodologies would be beneficial.

- **Aaron** asked **Annie** to comment on key components in terms of data sharing or a key agency that helped in the early days to get that bidirectional data going and be able to model that from an epidemiology perspective.
• Annie responded they had already done a lot of work on electronic laboratory reporting and automated delivery that were major supports to their surveillance system. They also established relationships with regional health information organizations (RHIOs) in New York City, which are aggregate stores of electronic health record data, and were able to leverage those relationships. They had to build ways to query those aggregate data and match them with their surveillance system. She explained that the electronic death registry data was critical, as well. Work needs to be done to improve their processes further and increase comparability across jurisdictions, on the interpretation of the data and sharing and aggregating data to the national level. Multiple streams of data need to be harmonized because they have conflicted and confused the public.

• Aaron mentioned feedback on work HITAC members Valerie Grey and John Kansky completed in their states’ HIEs. He asked Joseph about his experiences with state-level information being shared across state lines (Mississippi, Louisiana, and Texas) and critical components of this process regarding privacy and security or issues.
  o Joseph responded that part of Louisiana depends on a hospital/referral center in Texas, as it is closest, for hurricanes, evacuations, and during the pandemic. Automation typically stops at the state borders, resulting in manual processes that slow down work and increase complications.
  o Sam described how HHS Protect allowed border states to have access to other states’ data, though he stated they could have shared this information more widely. This work depended on working with states to determine if they would like to share information with the entire neighboring state or just neighboring counties. He stated that a takeaway is that they need to continue to improve the process to better support the next public health emergency response.

• Aaron asked Terra about how the HITAC can use vital statistics to better forecast and plan its work on initiatives, like adding data classes to future versions of the USCDI to emphasize health equality by design. He referenced work the NHS did in the United Kingdom to break down demographic information and allow patients to opt-in to sharing.
  o Terra explained that 57 vital record jurisdictions cooperatively participate and the Vital Statistics Cooperative Program with the National Center for Health Statistics. They adhere to standards in how we collect data, and the tools they use to collect data are advised by the National Center for Health Statistics and are shared with data providers. She discussed how race/ethnicity information on decedents is reported or collected from their loved ones. She suggested that allowing for flexibility at the national level regarding how people communicate this information would be helpful. States can then update their information.
  o Annie voiced her support for Terra’s comments and discussed the process she recently undertook to try to enable the people they interview to identify themselves instead of responding to preset boxes. A national conversation about this topic should be held. She discussed the example of people identifying as Latino or Hispanic while not identifying with other races.

• Aaron asked Joseph whether there were datasets, systems, or designs that were key in encapsulating equity by design for the rural parts of Louisiana related to urban. He asked if they used mass data collection, normalization, and extrapolation of analytics.
  o Joseph responded that Louisiana invested in resources and infrastructure that served marginalized communities ahead of time, partly due to the state’s experiences responding to large hurricanes.
• **Aaron** asked **Johnathan** about how providers can reach out and ask for assistance with materials management. Can infrastructure for sharing information with the community be put in place in advance, even if data shared are not electronic? How can they include everyone (small and large, rural and urban, etc.) to level the playing field?
  - **Johnathan** responded that FEMA handles national responses, and they partner with the FEMA regional representation, as well as the ASPR Regional Emergency Coordinator Cadre, which is the first point of contact to gather information and bring it back into a coordinated fashion. During the height of the COVID response, FEMA led the operation, and as time moves on, they are handing control back to ASPR. They have recognized the need for a standing way of doing business for the future and are working to build it.

• **Aaron** asked **Joseph** and **Annie** for feedback on which data elements/data elements/data sets should be considered differently (like adverse or allergic reactions) from a pediatric sense based on lessons learned from adult vaccinations.
  - **Joseph** responded that better data connections with smaller, private practices would be helpful since many teens are getting their vaccinations done in these settings.
  - **Annie** responded that children and teens can express disease, infection, and other potential reactions to vaccines differently than adults, so she suggested that there should be a better way to capture population-wide responses to the vaccine (not just individual). She emphasized the importance of the distribution of vaccines.

**TECHNICAL AND INFRASTRUCTURE ISSUES: CURRENT STATUS AND FUTURE NEEDS**


**Mary Beth Kurilo**, MPH, MSW, Senior Director of Health Informatics, American Immunization Registry Association (AIRA), introduced herself and presented comments on behalf of AIRA. View her presentation here: https://www.healthit.gov/sites/default/files/facas/2021-05-13_Mary_Beth_Kurilo_Presentation.pdf


**Christopher Harrison**, MPH, State Registrar and Deputy Director, Data Integrity & Analytics, State Office of Vital Records, Georgia Department of Public Health, introduced himself and presented on Georgia’s electronic death registration system and experiences during the response to the COVID-19 pandemic.
Discussion:

- **Les Lenert** asked **Karen DeSalvo** about Google’s exposure notification app and her experiences working on it for the past year. Will it be part of the essential, patient-driven public health infrastructure in the future?
  - **Karen** responded that Google’s exposure notification system is an interoperable API that they created with Apple to enable the use of Bluetooth low energy to let one phone know if it was within six feet for more than 15 minutes of another phone that may have reported (to an anonymous encryption key server) that the phone owner had a positive test. The API uses the most privacy-promoting path possible and has been set up in over 40 regions and countries; half of the states in the U.S. are using exposure notifications. Some states built their own apps. She described how the data is encrypted and noted that their experiences around the world showed that likely thousands of deaths and hundreds of thousands of infections were averted. However, they learned that the vocabulary and openness of the public health infrastructure, particularly in the U.S., have some gaps. She stated that the U.S. has to build the capacity and capability in the workforce itself to be able to receive or build or act on the technology tools that become available. She added that the typical health challenges facing populations in the U.S. are not about communicable diseases causing morbidity and mortality, but rather chronic disease and the SDOH as big drivers of morbidity and mortality. Better forecasting and epidemiology tools are needed, but the U.S. should also focus on building everyday surveillance systems to monitor chronic disease and a need to work to learn about people’s lifestyles, work, communities, and environmental drivers for illnesses.

- **Mary Beth Kurilo** voiced her support of Karen’s comments about the need to invest in the public health workforce and making space for well-trained and well-equipped staff to be present in critical conversations.

- **Karen** added that there should be a focus on building the pipeline and supporting the incumbent workforce. Funding will be needed.

- **Hans** agreed that technology is essential but not sufficient; policy agreements need to be in place to allow data to connect to technology systems.

- **Aaron** asked **James Watt** to comment on how California used communication and platform-level syndromic surveillance to successfully connect high infection rates to high rates of vaccination.
  - **James** responded that California worked to bring together different data streams at the small, sub-county levels, which has helped them look at cases, immunization delivery, and healthcare utilization to better direct responses. They have struggled with the quality of data and how to display and overlap data to make strategic decisions. They also need to focus on how health equity is connected to geography to deliver service through an equity lens.

- **Robert Wah** thanked the panelists and asked them to consider the interface between public health data systems and patients/the public. He discussed his recent work as chair of the board of the Commons Project and their recent releases/COVID-19 response efforts, including the release of CommonHealth, COVIDCheck, and CommonPass. He stated that patients now want to have access to their vaccination status and described recent work with the Vaccine Credentials Initiative (VCI) to determine how technology can be used to help the public access their vaccine status electronically in a way that is secure and is not proprietary. He explained that they want to make sure that they provide it in a very low-tech ability way to ensure access and promote health equity. He asked the panelists how to go about connecting this new area of the public health system directly with individuals.
Karen referenced her time as the National Coordinator for Health IT in 2015 and stated that this is an opportunity for ONC/HHS and the CDC to think about how they can work collaboratively to improve access to data that informs the care experience and the health journey of people and of communities. She referenced ONC’s past strategic plans that emphasized the need for the patient at the center and the need for people to control and access their own health data. Data on population health comes from making individual data anonymous and aggregating it, and she discussed examples of this work. She emphasized that language matters; data is in service to the public, not healthcare, and there are other good sources for data beyond the EHR. If these sources are not of the same caliber of EHR data, work needs to be done to modernize them. Finally, the entire focus cannot be on interoperability with the healthcare system because they will miss other sources of information about public health.

Mary Beth added that vaccine credential initiatives are important and agreed that consumers need access to their data. Lack of standardization and authentication issues have been stumbling blocks beyond a common method for accessing one’s own data. She discussed the need to authenticate patients as they try to access their medical records and then the need for standardization around the way ancillary systems interact. While she appreciates work on CommonPass and the VCI, which is open-source, federal guidance is needed.

Hans discussed the range and variety of systems that need to be brought together from a patient’s/consumer’s perspective. He stated that it is not how this information is brought together from a technical standpoint that matters most, but the ease of access and experience of the interaction for the patient. He discussed the need for patient identification across systems, noting that many questions still have to be addressed toward the goal of having a single, virtual health record from a patient’s perspective. Public health data needs to continue to be prioritized and championed in the rulemaking process.

Aaron asked Christopher Harrison to comment on the struggles states face as they attempt to return to normality in the coming months and Georgia plans to query immunization registries for datasets and then standardize, normalize, and present data back to businesses state to set a baseline for making decisions around the percentage of the population that is vaccinated.

Christopher responded that Georgia has publicly available information at a certain level that’s deidentified, but it is not queriable in a single location. He suggested several existing and potential solutions, including the COVID-19 dashboard, public health statistics, FHIR-based standards in querying a public-facing API, and providing documentation for use.

Aaron asked Karen to comment on using Google Maps to show testing and vaccine locations within the map. Does she have solutions the other panelists could incorporate, and does she see a use for consumer technology along with EHRs?

Karen explained that Google’s role in public health is that of a megaphone to promote messages from public health via Google Maps and parts of YouTube. Getting people who search on Google to the right public health messages is also part of their work, and the partnership between tech and public health is very important, though it has been awkward at times. Additionally, Google has novel, real-time signals, like search keywords, that are useful to public health and for building forecasting tools. She explained that data that surfaces in Google searches and tools need to be added into their systems intentionally, so they have focused on equity by ensuring that the federally qualified health centers or some of the rural sites have current, updated information updated that it is accurate on Google Maps when people are doing a search.
• **Arien Malec** echoed a previous comment that weighed the need for policy levers to orient data while also considering how to get data to flow to enable policy. He discussed his support for California’s COVID response, policy frameworks, and the color-coded alert system, but he noted that efforts there missed signals relating to primarily Latino-based communities in various parts of the state and who were also essential workers, as they were hit heavily by the pandemic in fall 2020. He asked how they could determine which early signals to track (maybe using SDOH), which policy levers could be put in place to catch other early signals, and how to connect the signals to policy levers in the future.

  o **James** responded that lack of data completeness and gaps in reporting around race/ethnicity led to the missed signals that the Latino population would be hit harder by the pandemic than others. He suggested that new regulations need to be established for collecting this information from hospitals and labs. Similar data gaps occur in relation to collecting occupation data. In the beginning, they also struggled with getting data to flow effectively from their surveillance systems and lacked communication tools, like visualizations and other ways to make data flow bidirectionally, especially locally.

  o **Mary Beth** noted the importance of having the work/time/resources necessary to properly analyze data and make good program state and federal decisions accordingly and in near real-time. A lesson from COVID-19 is that the workforce needs to be reinforced, and systems need to be funded to adequately address health equity concerns.

  o **Karen** referenced her previous experiences releasing a report via the National Academy of Medicine on 21st Century Public Health and suggested that capacity and capability could be shared between public health departments for data science and data visualization purposes.

  o **Hans** responded that EHRs have a critical role in helping pull data together to gather insights. He suggested that they need a better understanding of the kinds of questions posed to different systems, explore ways of engaging and interacting with them and determine the kind of access needed to enable this work to happen more quickly.

During the break between panel presentations, **Aaron** paused before beginning the next panel discussion to allow **Steve Posnack** to announce that the Biden-Harris administration had just put out an announcement regarding $7 billion from the American Rescue Plan that will be devoted towards hiring and training public health workers in response to COVID-19 and described a number of different investments that are being made.

**LEGAL AND POLICY ISSUES: CURRENT STATUS AND FUTURE NEEDS**


**Nicholas Soulakis**, PhD, Chief Public Health Informatics Advisor to the Chicago Department of Public Health, introduced himself and presented on the current status and future needs of public health informatics in Chicago. He discussed the question of real and/or perceived barriers exist that continue to inhibit progress in integrating public health and clinical data sources while responding to public health emergencies. View his presentation here: [https://www.healthit.gov/sites/default/files/facas/2021-05-13_Nicholas_Soulakis_Presentation.pdf](https://www.healthit.gov/sites/default/files/facas/2021-05-13_Nicholas_Soulakis_Presentation.pdf)
Lance Gable, JD, MPH, Associate Professor of Law, Wayne State University Law School, presented key themes and resources for data in public health emergencies. View his presentation here: [https://www.healthit.gov/sites/default/files/facas/2021-05-13_Lance_Gable_Presentation.pdf](https://www.healthit.gov/sites/default/files/facas/2021-05-13_Lance_Gable_Presentation.pdf)

**Discussion:**

- **John Kansky** applauded Chicago’s work to connect hospitals to share standardized data to benefit public health and asked **Nicholas Soulakis** to comment on whether these connections could be used as the basis of establishing an HIE for Chicago.
  - **Nicholas** responded that they have drawn from examples of HIEs around the country, noting that the Illinois HIE had an untimely demise, and explained that they look forward to building an HIE or some sort of public health information exchange, including standards to exchange health data. He mentioned eCR as an example and explained that they will begin asking their partners to think about eCR going forward. Their HIE plans are dependent on the community’s needs, which will evolve. He also called for greater integration of social services on HIE.

- **Sheryl Turney** highlighted some items in the ecosystem that are still lacking or may be improved, which included a consumer perspective on how their data is being reported and used (similar to checking financial credit scores), attaching third-party tools to patient accounts, and considering how this information is used in the ecosystem, the need to build public health reporting into the federal/state ecosystem by improving data connections, and data should be exchange in a more timely, consistent fashion where it is not custom-developed for every entity. She referenced developments in financial communication, including the availability of apps and the ability to link accounts, as models of progress for healthcare.
  - **Lance Gable** agreed that these were important goals to pursue and commented on legal and legislative requirements necessary to facilitate such a process, noting that it would still be subject to federal regulations that attach to health information privacy. He suggested that there needs to be an evaluation of how both the existing and potential future legal regulations of information that attaches to the type of ecosystem **Sheryl** described. They will need to continue to protect privacy in a robust way.
  - **Denise Chrysler** agreed with **Lance’s** comments and added that she has refused to use an app to bring together all of her own health information because she knows that privacy protection laws do not govern an app. Data and privacy policies would need to be examined.
  - **Nicholas** discussed lessons learned from health departments’ work during the pandemic to design and launch apps for their constituents, noting that there have been positive aspects but that it has been more challenging to use all the correct standards and translate public health programs successfully on compressed timelines/under pressure. Health departments need to get better at developing mobile, customer-facing apps. Also, even if a successful, state-wide, consumer-facing app is launched, some counties and jurisdictions legally interfere with the effective flow of data. He stated that when apps are thwarted by jurisdiction, they need to work to understand all of the use cases.
  - **Lance** cautioned against letting the issues **Nicholas** described languish and using the financial and public support that are now available to make focused and deliberate changes.
• **Aaron** asked the panelists if the HITAC’s future work on USCDI standards around privacy and security can help to regain lost public trust and assure them that their data is not being used for any other purpose other than public health and response purposes? He also asked them to consider if there is a better definition of the data, issues around data provenance, and how data is being used? Are there considerations from a legal compliance perspective that the HITAC should consider around these data elements?
  
  o **Lance** stated that there are existing privacy regulations that apply to some data being discussed and explained that there is inertia in the existing HIPAA privacy consent process, meaning patients do not engage in a dialog with what it means for the protection of information, especially for downstream uses like public health reporting. Because the public does not seem comfortable sharing certain types of information, ensure that laws are in place to protect against discrimination based on health information. He suggested that because non-government entities play a role during data collection (through apps) or downstream, they need to determine if new health privacy laws apply.
  
  o **Denise** discussed hesitancy in releasing data because of the risk of reidentification and approaches states have used through laws to collect and share public health data. She suggested that developing robust data release policies that assess the risk of reidentification and the importance of state legislatures looking at the balance between maximum support of privacy and informing the public by sharing information.
  
  o **Nicholas** discussed the web of privacy laws that come into play to protect end-users and noted that it takes time and careful legal and informatics analysis to interpret these laws, especially when several apply to a case. Work is being done, and laws are being passed on a compressed timeline, but the legal work of clarifying further ambiguities in HIPAA should continue. He emphasized his role in this work as that of an informatic officer, not a lawyer.
  
• **Aaron** asked the panelists to comment on the intersection of FERPA and HIPAA as it relates to public health work and responses in the future.
  
  o **Denise** responded that FERPA is much more restrictive when it comes to providing information to a public health agency than HIPAA is, but HIPAA says that if FERPA applies, then HIPAA does not apply. She discussed the variety of provisions HIPAA has about sharing identifiable information with public health agencies for various different purposes and explained that FERPA does not have all the same provisions. She described some of the FERPA provisions that permit data sharing with schools and noted that the data then belongs to the school, not public health.
  
  o **Lance** added that there are opportunities for partnerships, going forward, between public health departments and schools, especially the younger population is approved to receive vaccines. He suggested that academic institutions might use this information to achieve outreach and get more people vaccinated. He explained that the legal precedent says that states have the authority to require vaccination, but there is ambiguity around one that has been approved for emergency use. Some states are creating legislation that says otherwise, and the law is in flux.
  
  o **Aaron** responded that he misspoke and meant to refer to FERPA and HIPAA.
  
• **Clem** emphasized the need to move quickly and stated that some privacy issues should not trump 500,000 lives lost to the pandemic.
  
  o **Denise** responded that privacy concerns often come up when data are shared with non-public health organizations, community leaders, and the public.
  
  o **Clem** urged for someone to make the process less complicated.
Lance responded that, though health departments have spent the recent weeks trying to increase vaccination rates and operationalize vaccination points of dispensing at great speed, they still have to do their due diligence to make sure that vendors will protect data appropriately. He added that since they are specifically addressing public health emergencies, it will always be a compressed timeframe with very rapid decision making and risk assessment.

Clem referenced the need for greater speed in public health responses and referenced the time the FDA took to approve the vaccines in the U.S. versus the amount of time to approve in the U.K.

CREATING THE PUBLIC HEALTH ECOSYSTEM OF THE FUTURE

Joneigh Khaldun, MD, MPH, FACEP, Chief Medical Executive for the State of Michigan and Chief Deputy Director for Health in the Michigan Department of Health and Human Services (MDHHS) introduced herself and presented information about MDHHS’s experiences and response efforts during the COVID-19 pandemic and recommendations toward updating its public health ecosystem.


Ken Mandl, MD, MPH, Director, Computational Health Informatics Program at Boston Children’s Hospital & Harvard Medical School, introduced himself and presented testimony on the interplay and intersection between virus surveillance systems and application programming interfaces (APIs), which turn electronic health record systems (EHRs) into platforms for running apps and exchanging standardized data on populations. View his presentation here: https://www.healthit.gov/sites/default/files/facas/2021-05-13_Ken_Mandl_Presentation.pdf

Eric Topol, MD, Founder and Director of the Scripps Research Translational Institute; Professor, Molecular Medicine, and Executive Vice President of Scripps Research, introduced himself and participated in the panel discussion session.

Discussion:

- Clem McDonald asked that the process for scheduling vaccine appointments discussed by Jim Daniel be made even faster than the process for booking airline tickets, which was the comparison Jim made during his presentation.
- Sheryl Turney inquired about how the AWS cloud technology strategy would work and would be implemented so that all constituencies (states, federal, etc.) have access to the same technology and solutions.
  - Jim Daniel responded that a third-party convener would be needed to connect state and local government and mentioned the Association of Public Health Labs that is running the AIMS platform. He explained that there are two examples of a shared federal-state infrastructure running on the AIMS platform, including eCR and one for syndromic surveillance. He also described an ONC project called Immunization Gateway that promotes sharing immunization data between states, consumers, and the federal government to have access, where appropriate.
- Aaron asked Eric Topol to comment on things the HITAC should consider in terms of data standards, elements, and other items to accelerate in the future that might become a part of a new USCDI standard.
Eric stated that the difficulty is integrating multidimensional data and then feeding it back to users. Using artificial intelligence (AI) on multidimensional data is a work in progress but would provide a great service by controlling or preventing outbreaks.

Ken Mandl suggested that public health take advantage of the opportunity to merge multiple types of data, including viral genomic data, and added that APIs are one approach to bringing multiple data types and systems together. Rich information can better inform public health decision-making.

Eric discussed how wearable devices, like Fitbits, can use sensors to pick up on COVID-19 symptoms, noting that over 700,000 people are donating their data in Germany to provide country-wide surveillance. Passive data collection is another layer of data.

Aaron asked Joneigh Khaaldun to comment on the area of mass data merging or mass data elements that could accelerate the discovery of new trends or new cohorts of patients. What public health tools can be designed today for the future?

Joneigh commented on her team’s process to get data from a wide variety of tools (Survey Monkey, Excel spreadsheets, Medicaid data, disability data, etc.) to complete their contact tracing and case investigation work. She stated that this process has been so burdensome, they have not had time to consider cool new apps.

Aaron responded that a public health platform that would connect via multiple secure APIs and OAUTH could aggregate data. Then, he asked Jim to comment from the AWS perspective on whether there are missing data elements, classes, or specifications.

Jim responded that the missing data elements are basic and have been mentioned by several others throughout the meeting: basic address and phone information from lab reports, SDOH, and comorbidities. AWS has worked to build data lakes, a cloud-based way to bring public health data together from multiple sources that are not API-based. It has helped some states.

Aaron asked Eric to comment on dimensions of cybersecurity or privacy the HITAC should consider, like those used by Germany, Israel, or others, as they build out data classes and elements in the USCDI to keep privacy and security at the forefront.

Eric described the use of federated AI, which can get data from health systems across the country without removing it, and homomorphic encryption and other tools to protect security and privacy. Israel only uses digital health records as a country, so that made it easier for them to do mass vaccination. The U.S. has a more segmented system, so it is more difficult. He warned the HITAC against letting IT companies rule the roost.

Ken commented that the 21st Century Cures Act and the ONC Rule implementing the API and Information Blocking Provisions could bring universally available digital data to the U.S. in specialized FHIR format within the next year or two. They will have to anticipate issues as they prepare, but he urged attendees not to underestimate the power of having data interoperability across all care sites in the U.S.

Jim echoed Ken’s comments and stated that FHIR Bulk Extract is a game-changer for public health.

Aaron asked Joneigh to comment, as a practitioner, on the promises on the horizon, as described by several of the other panelists. Should the HITAC make an effort to focus on bringing AI and machine learning to the forefront of its annual report?
Joneigh stated that, though the past year was rough, she is optimistic. She suggested that anytime someone needs to go to a home (as a social worker), they should address the family’s needs, including if they need COVID vaccines.

Ken spoke about the need to work on machine learning for public health surveillance and the potential for AI to be useful for defining the case of an emerging disease from large amounts of data. Parsing the clinical data to determine different presentations of COVID was a challenge during the early days of the pandemic, and AI could be helpful there. It is also well-suited to molecular diagnostics.

Clem commented on the recent importance of measuring air flow, in addition to wastewater analysis, to COVID-19 relief efforts and public messaging. He sees a use for machines in this work. Also, he thanked Jim Daniel for his work on AIMS, noting that it would be the basis for evolving work in public health, and thanked Ken for his work on FHIR. He encouraged public health to take advantage of healthcare standards and not build a siloed systems of their own.

Jim responded that the siloing often occurs at the state level due to funding, though states often know best what is needed at the more local levels. It raises interesting questions about being independent but also participating in an interoperable system.

Robert Wah asked about leveraging existing modalities, like wearable sensors, to get data from them to make other inferences, like managing chronic diseases. Can lessons learned from the pandemic be useful here?

Joneigh explained that she worked on a project during her time in Detroit that connected air quality to people who suffered from asthma to send public health alerts. This work was done with sensors in the community and could be scalable to address a number of health concerns. She cautioned the HITAC that people with chronic conditions might be doing more poorly as a result of the pandemic and might not be seeking medical care. They should work to build up chronic disease surveillance.

Eric echoed Joneigh’s comments and described a similar project on asthma in Louisville.

Lance mentioned the Environmental Public Health Tracking Network at the CDC that is underfunded and is working to build infrastructure across the U.S.

Ken added that the ability to engage patients through sensors, gain permissions at the point of data generation, and use data generated by active responses (surveys, etc.) is nearly untapped.

Micky asked Eric to comment on innovation related to various types of technology, discovery, and life sciences. Clem commented on the FDA earlier for taking longer to approve a vaccine than the EU. He asked for Eric’s thoughts about how to best harness public health data systems and real-world evidence (RWE) to shorten the time cycle from discovery to bench to the patient.

Eric commented that the FDA used tighter criteria than the EU and explained that the trials in the UK were done publicly. He justified the time it took the U.S. to approve the vaccines. He discussed how the pandemic has hyper-accelerated life science innovation, including work on mRNA vaccines and the largest clinical trial in the history of vaccines. He explained the importance of accelerating the BLA and discussed how having the BLA pending approval at the FDA would be important. Then, the military, health systems, and companies around the U.S. could make the vaccine mandatory. He emphasized that the work on regulatory science is part of the achievements.
INTEROPERABILITY STANDARDS PRIORITIES (ISP) TASK FORCE UPDATE

Arien Malec and David McCallie, the Interoperability Standards Priorities Task Force 2021 (ISP TF 2021) co-chairs, introduced themselves. Arien thanked the HITAC for the opportunity to present and referred to ISP TF’s timeline, roster, mission, and charge, which is grounded in the 21st Century Cures Act (the Cures Act). Details of these items were included in the ISP TF 2021 presentation slides.

Arien explained that the focus of the ISP TF 2021 was to identify opportunities to update the ONC Interoperability Standards Advisory (ISA). He explained that the TF prioritized interoperability needs based on ONC priority areas and assessed the standards landscape via multiple hearings for:

- Health Equity
- EHR Data Use for the “Learning Health System” based on COVID-19 experience in pragmatic trials, real world evidence, comparative effectiveness, etc. (e.g., UK RECOVERY trials).
- Burden Reduction and associated Clinical/Administrative Data and Standards Harmonization

Arien explained that the ISP TF 2021 also heard testimony on Public Health Situational Awareness and deferred recommendations for Public Health to the Public Health Data Systems Task Force (PHDS TF). Future TF work is warranted on the topics of Care Plans/Chronic Disease Management and Data Sharing Federal & Commercial Entities.

David and Arien took turns presenting and discussing the ISP TF 2021’s draft high-level recommendations, which were detailed in the TF presentation materials on slides #6 through #15, and covered the following topic areas:

- Foundational Standards – Fast Healthcare Interoperability Resources (FHIR)
  - FHIR CDS Hooks or triggering offline workflows via FHIR Subscription
  - FHIR Questionnaires
  - FHIR Consent Directive
- Foundational Standards – Common Data Models
- Foundational Standards – Terminology
- Healthy Equity
- EHR Data Use for Research, Real World Evidence (RWE), RECOVERY-like Trials, Comparative Effectiveness
- Harmonization of Clinical and Administrative Data for Burden Reduction
- Situational Awareness

The ISP TF 2021 will present its finding and recommendations to the HITAC at its meeting on June 9, 2021. A vote will be held at that time on whether to adopt the recommendations and transmit to the National Coordinator for Health IT.

Discussion:

- Sheryl Turney thanked the presenters and asked if a recommendation around breaking down the proprietary roles of patient portals would be within the scope of the ISP TF. She described challenges faced by patients who have not been allowed to bring their patient portal information together at one point of access, which would increase interoperability, and discussed related vendor challenges. Also, she inquired if the ISP TF would make a recommendation around the work the Gravity Project has done on social determinants of health (SDOH) and health equity, which plays a role in disparities related to vaccine distribution and testing.
Arien responded that this would be a good suggestion to carry forward to the next iteration of the ISP TF, as the TF has already endorsed Gravity’s work and supported recommendations made by the USCDI TF. The ISP TF has made recommendations around FHIR-based APIs and OAUTH2-based access. He described instances in which the burden falls on the patient to access their data across multiple portals, even when all of the portals are supported by the same vendor.

David supported Arien’s comments and noted that APIs could play a role in work related to Sheryl’s suggestion to use a portal as an aggregator.

Robert Wah stated that code sets that have been traditionally considered as useful for administrative purposes only, but it is important to recognize that they play a role in capturing data for public health purposes, too. He discussed his history with the American Medical Association (AMA) and their work on the Current Procedural Terminology (CPT) code set, which the CDC and CMS have used to create COVID-19 product and administrative codes used to track cases and vaccines administered. He discussed how CPT has been used internationally and encouraged the ISP TF to invite experts in administrative coding to present to the TF.

Arien responded that the ISP TF did not mean to endorse one code set over another and explained that they have endorsed the work of the Intersection of Clinical and Administrative Data Task Force (ICAD TF). Additionally, the ISP TF did hear presentations from the administrative side.

Clem McDonald submitted several suggestions to the ISP TF:

- Research is important but do not burden clinical practice with all of the same standards needed for research.
- Clinicians often use the billing code to create a Problem list because it is easier for them.
- The LIVD mapping tool has been aggressively used to map between instrument codes and LOINC codes/SNOMED-CT and as a reporting tool to public health agencies during COVID-19 relief efforts. However, it cannot be automated to any instrument in many cases.
- Arien responded that the TF’s recommendations would be clarified to reflect that work would be done to source normalize so that when work is done for clinical research, the data are not being renormalized. The research community provided testimony that the majority of work involves recoding and renormalization. The ability to source normalize would speed up that work and make the data available for research. Also, mechanisms for collecting additional information for clinicians are needed, but this does not drive the need for clinical care over research.
- David stated that there are data of high interest to researchers, like data on ventilator settings, that is already being captured but is not being exported.
- Clem commented that HL7 and Observational Medical Outcomes Partnership (OMOP) have already agreed to harmonize toward a common data model, and David agreed that they are working on harmonizing. However, other data models (I2B2, PCORnet) should also be considered. Clem added that PCORnet needs funding to make the conversion.
- Arien described how a lack of a common data model leads to lossy work and stated that it seems like PCORnet wanted to align with FDA Sentinel. This is why the ISP TF recommended that ONC align with other federal agencies and departments to leverage their ability to help standardized/align. Clem commented that Sentinel is private/secret.
PUBLIC COMMENT

Mike Berry opened the meeting for public comment two times during the course of the meeting: at 10:15 a.m. and 4:45 p.m. During the first public comment period, there was one public comment submitted by phone, and there were no public comments submitted during the second period.

Janet Hamilton, Council of State and Territorial Epidemiologists (CSTE):
Thank you so much. I just wanted to thank the panelists that just concluded as well as the ones from this morning. I am Janet Hamilton from the Council of State and Territorial Epidemiologists, and our epidemiologists are on the frontlines of the COVID response. I really wanted to harken back to a comment from Jim Jirjis on the last panel, where he said something along the lines of, and forgive me for the paraphrasing, that clinical staff time today is making decisions without all of the information in front of them, and if the information flow, we would have much better decision-making. And I think we could say the exact same thing for public health.

And I think it’s crucial that as a community and as a group, we start bringing these conversations together so that it’s less of decisions in healthcare and decisions in public health and then the best policy decisions that we can make to improve health for all. We’re making decisions in public health, missing 50% of race and ethnicity information. We’re not able to make the best decisions possible. And I think this is a good time for us to look at this in a new, different, holistic kind of way so that we can have better health for all. And I just really appreciate the discussion.

Jim Jirjis responded that the public comment brought to mind the saying, “Give me the information I need, when I need it,” and he added, “Nothing more, please.” Both choices of “winging it” and waiting cost the patient and the system.

Questions and Comments Received via Adobe Connect

Mike Berry (ONC): Welcome to the HITAC meeting! We are glad that you joined.

Mike Berry (ONC): Meeting materials can be found here: https://www.healthit.gov/hitac/events/health-it-advisory-committee-34

David Wierz: Good Morning - Hearing background music

Robert Wah: In the hold for operator

Janice Tufte: Good Morning Patient Collaborator from Seattle WA

Leslie Lenert: on hold for the operator

Leslie Lenert: still on hold

Ram Iyer - FDA: not sure how to connect the video, I joined as guest

Alexis Snyder: missed me-Alexis Snyder is here

Terrence O'Malley 2: I'm on the call. Thanks.

John Kansky: Steve's visual image is CUI

Aaron Miri: Welcome Ram!
Steven Lane: Ram, welcome to the HITAC!

Matt Heim: [https://www.healthit.gov/buzz-blog/interoperability/health-interoperability-outcomes-2030](https://www.healthit.gov/buzz-blog/interoperability/health-interoperability-outcomes-2030)

Andy Truscott: Welcome Ram, and thanks Matt.


Ram Iyer - FDA: Thank you all! I have to step out for a few minutes for a couple of critical meetings but will stay for most of the sessions.

clem mcdonald: I am here clem

Janice Tufte: GRAVITY and more

Leslie Lenert: Is the CDC/ONC FHIR Accelerator the Medimorph project?

Janice Tufte: There are multiple FHIR knowledge accelerators (Standards [sic], Value Sets ++) [http://www.hl7.org/about/fhir-accelerator/index.cfm](http://www.hl7.org/about/fhir-accelerator/index.cfm)


Janice Tufte: Hiw [sic] it Failed? Lack of [sic] Isolation and Quarantine services, Workforce shortages across the spectrum, Supply chain from Food to Commerce to Transportation

Janice Tufte: UDS measures do not fully capture what patients needs are


Leslie Lenert: open source methods can allow public health to work collaboratively and build capacity for informatics

Janice Tufte: Agile use might include easier contracting opportunities to hear from partners who do not have the capability or access to provide invaluable input (Patient Collaborators, Community members who are perhaps most affected by PH measures)

Leslie Lenert: It's also about creating an eco sysetm [sic] of vendors

Leslie Lenert: but building on an open platform

Jonathan R. Nebeker: There have been several attempts at a utility-like interoperability platform. In the last few years consortia of vendors have developed viable middleware. Some [sic] of these consortia have turned into not-for profit organizations. Other consortia are largely based on open-source software. I also represent VA on a standards support organization formerly called Health Services Platform Consortium and now called Logica. That organization built the beginnings of such an interoperability platform that is now mostly used as a testbed for FHIR applications. Meanwhile, DoD has already [sic] implemented some of these platforms. VA is trying to figure out our strategy. Timing is good now to advance interoperability through these more modern platorms..
Jonathan R. Nebeker: I also know that there is interest on Approps and VA oversight Congressional committees.

Leslie Lenert: amen

Abby Sears: Clem....I agree completely!!

Abby Sears: A person is not a disease

Leslie Lenert: cross program can never happen without [sic] cross platform funding

Ken Kawamoto: Clem - +1. I think it was only just this week or last that the CDC acknowledged aerosol transmission as an important transmission modality

carly babcock: Maryland has a great HIE (CRISP) that has been doing some good work with the state health dept

Brett Oliver: Clem and Ken - agree!

John Kansky: YEs -- kudos to CRISP. They are doing great work and a good model for multi-state HIE.

Leslie Lenert: aren't they? shows what the regional approach can do across stateliens [sic]

Leslie Lenert: lines

Leslie Lenert: prediction of where outbreaks will go to manage ramp up and allocation

Lisa Bari: I agree with this, Michael!

Janice Tufte: Good point categorically organized and funded

Lisa Bari: We need to fully fund public health data infrastructure work across the country - in all states and territories, and across states and regions.

T. Wilson: Bad polices and disparities in rural and urban communities.

Lisa Bari: Local leaders need to lead data modernization improvements, supported by the federal government.

Janice Tufte: RE Connectivity @TheFCC EBB Emergency [sic] Broadband Benefit opened yesterday https://www.fcc.gov/emergency-broadband-benefit-program

T. Wilson: Yes, health equity! Right Dr. Murray!

Alexis Snyder: Well said about health equity and provider behaviors

Leslie Lenert: perhaps public health needs to learn more about REDCap as a replacement for Epi Info

Jim Jirjis: Recap is superb

Leslie Lenert: It shares many of the same features of the system of the "golden age" with
HIPAA compatibility and interoperability

Jim Jirjis: REDCap

T. Wilson: Teach Dr. Murray!

Leslie Lenert: It is a great example of how open source can create capable highly used software

Janice Tufte: Yes Dr Murray! Race and Ethnicity is self atested [sic] or assigned this is a problem in our local county self atested [sic] 30-40% do not answer in some areas of PH

Jim Jirjis: Yes, my good friend at Vanderbilt, Paul Harris created it. Was a great story to see if rapidly go global

Leslie Lenert: Paul is a great friend and collaborator. We, at MUSC, have added Bulk FHIR routines to it

A. Fillmore: Strong public health data systems, requires cross-institutional data governance based on: 1) Trust; 2) Transparency; and 3) vested stakeholders.

T. Wilson: Yes!!!!!!

Diane Borhani: Dr. Murray is absolutely correct - we need the people that actually touch the data in the room. Until they understand the importance of what they are doing we will never have good and timely data!

Alexis Snyder: Yes! The human component!

Lisa Bari: Great choice for ASTHO President!

Michael Fraser, ASTHO: @Lisa, we agree! :-)

Greg Singleton: Thanks for the recognition for federal efforts Anne

Carolyn Petersen: +1 for Dr. Zink's comment re: systems serving patients rather than patients serving systems.

Alexis Snyder: +2

zhen lin: +3

Leslie Lenert: +4

Alix Goss: +5.

Janice Tufte: +6

T. Wilson: Sound is muffled

Mark McClellan: NC race/ethnicity vaccination tracking in service of explicit strategy engaging providers and public to address equity: https://covid19.ncdhhs.gov/media/2388/open
Leslie Lenert: "Proposed Changes to Public Health Reporting for Hospitals in 2022, Promoting Interoperability Program" Date Time: May 25, 2021 02:00 PM Eastern Time (US and Canada)

Leslie Lenert: CDC OSEL/CMS online presentation

Alix Goss: Great framing by these panelists for the 'corners we need to turn' to have effective Public Health integration and very analogous to the journey we've taken and barriers we have been tackling for administrative simplification and promoting interoperability through use of EHRs and HIEs!

Janice Tufte: @Lelslie thank you "The agency is floating new requirements for hospitals to report on syndromic surveillance, immunization registries, electronic case reporting and electronic reportable laboratory results." 5 25 21

Janice Tufte: Syndromic syndrome is so important from the patient level

Bob Harmon, MD: A good example of a national platform with national standards for electronic case reporting of nationally notifiable conditions from EHRs to state public health agencies and the CDC is the Digital Bridge project (www.digitalbridge.us).

Steven Lane: +1 re the value of Digital Bridge, which is now looking to develop an IG for a new use case, cancer registry reporting. Leverage what is working now!

T. Wilson: Minorities don't trust in governmental agencies and there is still discrimination and segregation in the health system. The haves and the have nots.

Grace Cordovano, PhD, BCPA: The words we use matter. Love framing to give space to emphasizing the importance of how to ask these important questions.

Greg Singleton: Re: Dr Fraser, we as the Federal gov't are working on the data transparency and feedback to states. The capabilities vary by states, and we work on the integration on a state by state basis

Lisa Bari: Many Americans don't trust government agencies. In fact, it's a theme across racial and ethnic groups in the US, for Reasons.

Janice Tufte: Yes make space is very important

Diane Borhani: This is an organizational issue - leadership does not value the work that the clerk at the hospital does and hasn't taken the time to train and educate in a way that helps them understand the importance of what they are doing.

Abby Sears: The FQHC market is known for how to break down the cultural barriers related to at risk and marginalized patient populations. There are organizations and groups of organizaitons [sic] that understand how to do this well.

Lisa Bari: Pushing for transparency and building trust LOCALLY is key to chipping away at that mistrust.

T. Wilson: Yes substandard healthcare has always been the issues regarding [sic] people of color.

Greg Singleton: +1 on importance of trust discussions
Abby Sears: I would really argue that there are groups that produce exceptional outcomes related to diverse populations.

Nicole Kemper: For what it's worth, there are more granular OMB categories for race and ethnicity, and to be certified, health IT products must support these categories at a minimum. There are more granular categories that can be included (think, drop down). It's up to the developer and the provider to implement those categories.

Steven Lane: We all have a tremendous opportunity to provide public support for the recent CMS NPRM https://www.cms.gov/newsroom/fact-sheets/fiscal-year-fy-2022-medicare-hospital-inpatient-prospective-payment-system-ipps-and-long-term-care which proposes requiring providers, as part of the Promoting Interoperability program, to "report 'yes' on four of the existing Public Health and Clinical Data Exchange Objective measures (Syndromic Surveillance Reporting, Immunization Registry Reporting, Electronic Case Reporting, and Electronic Reportable Laboratory Result Reporting) or requesting applicable exclusion(s);"

Jim Jirjis: Steven. I agree, but saying yes does not at this point mean connection. As I understand it, it means that you are "in good faith" working towards it. Thus far this had led to many connections not actually being operational

Jim Jirjis: Would like to see the incentive include actual connections in a manner that we are discussing. But funding and timelines and incentives are an issue...on the public health side

Carolyn Petersen: +1 to Bari. Also need to focus on effective communication to public to support the transparency on which the trust is built.

Leslie Lenert: Love the idea of adapting contact tracing software to provide data to the public on risk in near real time

Leslie Lenert: great work @Sarah

Leslie Lenert: Digital bridge is a great example of two-way data exchange for public health in an information ecosystem

Steven Lane: Public health jurisdictions [sic] have the option to utilize the Carequality Framework to query connected provider organizations through the Carequality framework: https://carequality.org/ Only in Washington State has this option been utilized in the context of the pandemic. This is a critical opportunity to improve provider-public health interoperability, allowing PH to query for needed data for case investigation.


Leslie Lenert: so do HIE's solve the many to many problem?

Deanne Kasim: Good question - what is the proposal for patient record/data matching?

Jim Jirjis: HIE RHIOS are similar in that they have tremendous variation

Jim Jirjis: hie
Arien Malec: In my experience, HIEs in the middle of messy systems have "sustainability" issues.

Jim Jirjis: In our 20 states we just finished an analysis of HIE (noun) RHIOs. They have very similar variation to public health departments

Jim Jirjis: If they become QHIN's as part of TEFCA they could be a part of the solution.

Arien Malec: If you don't standardize, making HIEs be the bridge just moves who has the pain.

Jim Jirjis: We are concluding that our hospitals [sic] really need to be able to connect to a national exchange that addresses what TEFCA is trying to address.

Genevieve Morris: When I put TEFCA together, one of the convos with CDC on PH was specifically that TEFCA doesn't solve the variation in the HL7 and data requirements we see across the states.

Genevieve Morris: It solves the transport [sic] layer issues but is agnostic on format

Jim Jirjis: The recent [sic] IPPS change to give 40 points to anyone who can demonstrate bidirectional exchange seems to be a forward step in incentivizing at least providers

Jim Jirjis: to connect. [sic] But where is the incentive for public health to similarly connect, for example

Jim Jirjis: but USCDI is trying to solve the terminology issues

Leslie Lenert: Better data is a start

Genevieve Morris: Yes but the state PH issues aren't really terminology either, it's format layer at least in my opinion

Leslie Lenert: But long run is changing the business model to work collaboratively on health with the health system. Public health amplifies its resources through collaboration.

Jim Jirjis: true

Leslie Lenert: network thinking rather than program thinking

Leslie Lenert: @Steve Lane--any data yet on how public health in Washington has used record access to enhance COVID care?

Steven Lane: @Les - No data that I am aware of.

Steven Lane: I would ask Bryant Thomas Karras MD (bryant.karras@doh.wa.gov)

Chris Baumgartner: Hi Leslie: WA State is going to pilot using the exchange query via our state HIE. The goal is to see how good the national exchange is at filling [sic] in missing contact or demographic data.

Chris Baumgartner: I work with Bryant.

Anne Zink: V-Safe was amazing! thank you for that!

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David McCallie: @Jim +1

Steven Lane: @Chris Baumgartner - Why is WA limiting initial implementation to filling in demographic data from LTPAC as opposed to leveraging the opportunity to query for clinical data from providers more broadly?

Alexis Snyder: Any other HITAC member having problem with call in getting dropped?

Steven Lane: While C-CDA based queries via the Carequality framework are limited, the opportunity to utilize this methodology could lay the groundwork for future queries and bidirectional via FHIR.

Anne Zink: Thank you Linda!

Sheryl Turney: thank you!

Leslie Lenert: @steve: I agree with transitioning this to FHIR. see our paper with the CDC pioneers Ninad Mishra and Saugat Kirki. [https://doi.org/10.1093/jamia/ocaa059](https://doi.org/10.1093/jamia/ocaa059)

Leslie Lenert: Suagat Karki

Alexis Snyder: Wow!

Chris Baumgartner: Steven - I think we want to start small with a specific use case that has hampered our case investigation, contact tracing and surveillance work. From there I agree it would also be good to understand the value of other clinical data we could access. We need to do some work to bring in case reports into our disease surv system.

clem mcdonald: hear hear to Jim's comments

Aaron Miri: Contact Tracing White Paper done @ UT Austin with the CDC: [https://www.cdc.gov/mmwr/volumes/69/wr/mm6926e1.htm](https://www.cdc.gov/mmwr/volumes/69/wr/mm6926e1.htm)

zhen lin: data democracy

Leslie Lenert: @jim: great definition of true situational awareness

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

Jim Jirjis: Micky, would love to demonstrate to you and your staff some of the tools we have built that allow us to manage hurricanes, shooters (Vegas) etc. As a microcosm of examples for what could be done writ large if we had such a system in place

Jim Jirjis: as a nation

Corinne: MU also excluded national labs from the requirement (just focused on hospital labs).

Jim Jirjis: good point

Chris Baumgartner: I can't get the slides to download. It keeps asking for a login and I didn't have to login to join the meeting.
Krystal Collier: @Linda great comment aout [sic] MU

Krystal Collier: about*

Linda Sanches: the slides are available on the HITEC website

Chris Baumgartner: Thanks Linda

Steven Lane: Standards for Race and Ethnicity ARE included in USCDI Version 1: https://www.healthit.gov/isa/uscdi-data/patient-demographics#uscdi-v1

clem mcdonald: hear hear !!!

Jim Jirjis: fantastic point Arien

Genevieve Morris: @Arien is right, there are standards but they’ve been customized by the states or not implemented per the standards

Jim Jirjis: and the interpretation around the connections

Steven Lane: Perhaps TEFCA will be the vehicle to bring public health up to the same USCDI standards that providers must already support.

Jim Jirjis: yes!

Aaron Miri: reminder about the trending hashtag #HITAC

Mike Berry (ONC): Materials from today’s meeting can be found at this link: https://www.healthit.gov/hitac/events/health-it-advisory-committee-34

Micky Tripathi: Great morning, thank you everyone!

Steven Lane: Great running thread on Twitter @Arien!

Andy Truscott: Arien is Mr HIT Tweeter ;)

Linda Thomas-Hemak: This has been an amazing conversation and experience that in so many ways generates stabilizing energy of recovery necessary to transform the ubiquitous trauma of the COVID-19 dark pandemic into a brighter, preferred future [sic] for our country. Gratitude to all!

Matt Becker: Agreed, it’s been super helpful @Arien.

Arien Malec: thanks!

Leslie Lenert: impressive work in LA

Leslie Lenert: particularly linking IIS with DMV resources to enhance data completeness

Aaron Miri: @les - agreed! I wonder if the DMV ID number becomes the primary key and thus a unique patient identifier, [sic] of sorts

Leslie Lenert: great insight--all hazards response requires insight into the medical supply
Leslie Lenert: can't decide when to use the stockpile without knowing what is in the supply chain

Leslie Lenert: representation of occupations in EHRs continues to be a weak point in standards

Arien Malec: Oh, hey, David McCallie proposed using strong identifiers as tokens for linking, oh, a decade ago, and we built into CommonWell, but nobody is using b/c source capture is missing. [sic]

Aaron Miri: @arien - There's a lot on the national HIE's. We need all participants on said HIE's to also feel the same way

Steven Lane: Date of Onset - A new proposed data element for the next version of USCDI.
https://www.healthit.gov/isa/uscdi-data/date-diagnosis

Steven Lane: Sorry - Date of Diagnosis. Date of Onset is also submitted, but not yet proposed for inclusion in USCDI V2.

Leslie Lenert: https://ieeexplore.ieee.org/stamp/stamp.jsp?arnumber=8332475

Fern Johnson-Claire: Are we frozen?

Arien Malec: "We need all participants on said HIE's to also feel the same way" YES

Leslie Lenert: Cause of death reporting from EHRs via FHIR is another opportunity in vital statistics

Aaron Miri: @les good question pls raise your hand

Steven Lane: So exciting to see advancing public health interoperability leveraging HL7 FHIR.

David McCallie: @arien, @aaron - we probably also need those pesky incentives....

Terra Abrams Ankrah: Thank you @steven

Aaron Miri: @david that's one thought.... or.... we start getting a bigger stick and stop paying for absolutely everything...

David McCallie: @aaron - well, that's certainly an incentive -- no data, no payment

Aaron Miri: @david - 10/10 score.

Diane Borhani 2: Yes, no data no payment; also we need to standardize coding and have that come directly out of the medical record

Linda Thomas-Hemak: This pioneering work to advance collaborative integration of vital statistics data platforms is awesome and can be force multiplied by deeper layer integration into the care delivery workflowdata [sic] platforms with the interface being the sacred death certification process.
Terra Abrams Ankrah: agreed @diane

Terra Abrams Ankrah: a national coding engine would be useful

Krystal Collier: @Leslie agreed on the representation of occupation in EHRs. Based on some of the lessons learned in syndromic surveillance the collection of occupation data was something that became more readily available from those facilities and EHR vendors that could provide this information for the pandemic. The issue has really been around how to collect the data in a standardized way from data submitters but then also to have our receiving syndromic surveillance systems be able to accept and allow for us to query the data. It would be really helpful to have a process of how to collect and receive new fields in a standardized way during a public health emergency. This is also a field where it has not been added to the USCDI v2.

Diane Borhani 2: This is really the key - mandating electronic registration

Annie Fine: At NYC DOHMH we ran a daily match with our electronic death registry system and it was incredibly helpful. We are working on next step - to use automated data exchange using FHIR for this going forward.

Terra Abrams Ankrah: we did the same in DC @Annie

Leslie Lenert: It is important to remember that death certificate data is not directly derived from the EHR and may reflect social acceptability bias when the provider knows the patient or his/her family

Terra Abrams Ankrah: very good point

Genny Luensman: @Leslie @Krystle NIOSH has a construct called Occupational Data for Health (ODH) that includes collection of standardized occupation (and industry, similar to workplace). It is in part reflected in USCDI level 1 “work Information” data class.

Leslie Lenert: So, the type of linkage described in NYC, particularly linked to AI for recognition of new or unexpected syndromes is an important capacity

Diane Borhani 2: Yes, that is true - which is why we may need to consider splitting the tasks of certification from data reporting. If the EMR is standardized on how to report COD from a medical / ICD perspective that data could go directly to NCHS while the certification continues to go to the state

Terra Abrams Ankrah: DC vitals also has a field audit team to validate what has been entered into our EDRS by reviewing the medical record

Diane Borhani 2: Critical task for good quality data @Terra

Krystal Collier: @Genny the work NIOSH is doing is extremely helpful. However we need it adopted and more widely available in the base EHR so that we can have it pulled into downstream data streams like public health registries including syndromic surveillance.

Leslie Lenert: NIOSH work needs to be simplified for use in clinical care

Terra Abrams Ankrah: Diane makes a very good point about reporting vs. certification

Terra Abrams Ankrah: many data providers view their role in vital event reporting as
providing data for the eventual certificate that the family will receive.

Leslie Lenert: @kanter is right. Invest wisely now. which is why we are here.

Leslie Lenert: would a demonstration project using the same FHIR app to report death across states be a useful to identify issues with standardization?

Terra Abrams Ankrah: Yes, indeed.

Terra Abrams Ankrah: i believe this has been explored/demonstrated at connectathon.

Sheryl Turney 2: this is really great information.

Jeff Greenland (he/him), Axiell: @Leslie and @Terra - yes, that type of functionality has been attempted (and somewhat proven) at Connectathon events, which is really encouraging and impressive. However, I feel that it has revealed the inflexibility [sic] of institutions in the standards. Not because they don't WANT to be flexible, but because they are legally legislated to do specific things.

Jeff Greenland (he/him), Axiell: For example, if one jurisdiction legally allows "Unknown" as the gender, but a receiving facility doesn't support (or allow) that type of data, then things break down. And even if both want to be able to support it, there are the legal implications that are much harder to change than a line of code or a quick configuration value.

Linda Thomas-Hemak: Lessons should similarly be learned from the floundering HIE cancer surveillance registry initiative. The onerous reporting details required for primary care to even submit basic information to activate a patient with a new cancer diagnosis. This details that preclude reporting including relevant clinical staging data that should be the responsibility of Oncologists and extensive questions of how long people lived in their current home and neighborhoods and similar conversations about their current and past employment, etc. We need a real time, actionable cancer diagnosis and status registry that should be collectively stewarded with EHR and HIE visibility and also integrated with the vital statistics platform.

Steven Lane: Next slide.

Steven Lane: Slide 3.

Steven Lane: Slide 4.

Sarah Greene: Love the hopeful coda, Karen!

Krystal Collier: @Dr. DeSalvo thank you for that last slide!

Steven Lane: @ Hans - Great core recommendations! Need to engage OCR in clarifying privacy requirements.

Jess Kahn: Chiming in on previous convo re linking IIS to DMV- not everyone has a DL/state ID- and not everyone got vaccinated in the state where they have a DL. Could be one of several options but not sole option.

Leslie Lenert: Excited to be working with AIRA on bulk FHIR as a tool to facilitate population health practice. Bulk FHIR may help IIS deal with the demands for data they are facing.
Mary Beth Kurilo: Dr. Lenert, we agree! Great possibilities there.

Leslie Lenert: A bit of background for folks from a paper on this idea: https://doi.org/10.1093/jamia/ocab066

Aaron Miri: Identity Matching are key

Steven Lane: Q for Dr. Watt: What is required and when will CalREDIE be able to receive Electronic Case Reporting feeds, now being sent to APHL, so that providers can stop parallel manual case reporting and build on our investments in eCR for COVID to all reportable conditions?

Leslie Lenert: For folks who are interested, we've built a REDCap instance designed to work with IISs to support population health. It can work via either bulk FHIR or the CDC SOAP interface.

Terra Abrams Ankrah: Hi Chris! :)

Leslie Lenert: It seems like the California system might be the foundation for a platform for public health operations

James Watt: Thanks for the question about eCR. that is an area where we have struggled with limited system flexibility. we are working on a couple of different approaches to consuming the eCR data. Not sure when that will be on line so that parallel reporting can be stopped, but working on getting that done.

Aaron Miri: @james - amen. I tried hard but the counter forces need alignment on importance

Terra Abrams Ankrah: agreed @karen

Aaron Miri: 1000% agree on training the next generation of public health workforce

Krystal Collier: @agree Dr. DeSalvo

Steven Lane: Early in the pandemic there was great enthusiasm [sic] for eCR implementation and great progress has been made with both Cerner and Epic customer organizations live on automated reporting for COVID-19. The pace of implementation has slowed as the sense of urgency has abated and focus has shifted to vaccines. The ability for providers to replace manual case reporting with eCR is a tremendous incentive to prioritize and accelerate the implementation of this now standardized technology solution. How can we incentivize PH jurisdictions to accept this data and relieve providers of the burden of manual reporting?

Brett Oliver: I would add to Steven to say that the states were not ready for eCR. We worked tirelessly at the urging of the federal government only to find our state (KY) unable to connect

Krystal Collier: @Steven-I think some of this comes down to capacity for our workforce. We have a lot of resources that have been dedicated with COVID but how does that expand beyond COVID? How can we sustain workforce capacity [sic] beyond the one disease or condition focused on for a pandemic during a national emergency. I would say
eCR is not the only public health registry we need to think about these questions for.

Alexis Snyder: Protection through authentication is key, but saying we need one common place doesn’t work, just as there is no one common type of patient there can not be a common source to gather data. There needs to be a variety of ways for folks to access their data, especially for those without technology.

Alexis Snyder: “excuse the typos-working with a broken wrist :)

Carolyn Petersen: +1 to Alexis’ comment, and addition that there is no one “patient”. Patients are individuals and have different needs and goals, and One Size Fits All doesn’t - accessibility and a range of options are needed. We also need to consider caregiver use cases in which someone else (with patient’s agreement) accesses/manages/uses the patient’s data in service of the patient’s goals.

Alexis Snyder: exactly my point Carolyn, no one type of patient

Alexis Snyder: +1 to caregiver access

Aaron Miri: DS4P is a key concept with public health. Should not be all or nothing.

Linda Thomas-Hemak: Dr. DeSalvo’s comments on regarding “in service not to the EHR and healthcare but in service to the public” was very powerful. This type of transformational vision will empower and tap the capacity of patients for oversight of and meaningful contributions to their healthcare and frankly a welcomed, substantial work redistribution that right minded health care providers will embrace.

Robert Wah: Agree there is no single definition or requirement for patient. We need to get more information into the hands of individuals and empower/engage them to use this information to improve and maintain their health.

Brett Daniel: “Like” Linda’s comment :) Would add that equity is not a neutral stance, but an intentional mindset.

Riki Merrick: Need to make sure we focus on getting the data from the places where they are initially collected - needed for normal business needs rather than pushing it into workflows, where connections to PH are established (like ELR), but where those data elements are not needed for regular workflow.

Jess Kahn: Love the shared services comment- would be great to see states take this opportunity to build informatics infrastructure that spans PH, Medicaid, safety net programs, etc.

Carolyn Petersen: Can the URL of the paper Dr. DeSalvo referenced please be posted here? The captioning doesn’t seem to scroll back far enough to get that. Thanks!


Chris Harrison: That’s tremendous to hear about the resource funding for training and workforce development

karen desalvo: WOOT!!!!
Krystal Collier: Thanks Steve!

Bob Harmon, MD: Great news!!!

Steve P (ONC): "the Office of the National Coordinator for Health Information Technology will invest $80 million to train public health professionals to help modernize the public health data infrastructure, with a focus on recruiting from minority serving institutions and universities."

Julie Maas (EMR Direct): Great news, Steve!

Jess Kahn: that’s awesome!

Mary Beth Kurilo: Great news - thank you for sharing, Steve! Public Health is doing an amazing job under challenging conditions right now, so this investment will really help support their work.

Denise Love: good news—hopefully the recruitment will supply both traditional and non-traditional data systems/entities as the focus of public health information needs broaden

Linda Thomas-Hemak: YAY! This is an empowering validation of the ONC's and HITAC's leadership and vision demonstrated today. Public health impact potential is super exciting!

Denise Love: Totally agree with Sheryl Turney

Steven Lane: Many suggestions have been made re new data elements to support Provenance: [https://www.healthit.gov/isa/uscdi-data/provenance#uscdi-v1](https://www.healthit.gov/isa/uscdi-data/provenance#uscdi-v1) Those with interest/expertise should provide public comment.

Steven Lane: E.g., [https://www.healthit.gov/isa/uscdi-data/purpose-capture](https://www.healthit.gov/isa/uscdi-data/purpose-capture)

David McCallie: It seems like cultural resistance has trumped the privacy issues, at least in the last few years

Denise Love: Mental health/substance abuse data are essential to public health actions as well, learning how to navigate 42 CFR is important to PHA

Aaron Miri: @denise - Great point. This is crucial

Nicholas Soulakis: @Clem McDonald could not agree with you more on the cost of allthis [sic] deliberation. We take it hard too. We read the same news, and often bare the same personal burdens.


clem mcdonald 2: Cheers f or Ken's great work. And indeed, lets cash in on the rich trove of medical record data for public health purposes.

Julie Maas (EMR Direct): Many implementers are looking to UDAP (Unified Data Access Profiles) to securely scale APIs.
Nicholas Soulakis: I would love to hear more from public health agencies making progress on HIE with social services organizations, especially main street store fronts.

Chris Baumgartner: Can the new information blocking provisions help Public Health in receiving mission critical data? When we have standards available and reusable transport like HIEs available why do we still see resistance to interoperability?

Chris Baumgartner: @ Jim Daniel. Good to see you Jim. Do you see leveraging APHL AIMS as a QHIN as a way to continue to leverage shared infrastructure for public health?

Jim Daniel: Yes, Chris I think that is a great idea and I believe they exploring it.

Krystal Collier: It would be amazing if all our public health surveillance systems registries were building/enhancing their systems with the use of APIs. I can't say how much is possible based on what we can do in the BioSense Platform NSSP ESSENCE and our ability to leverage use of our APIs.

Denise Love: We need a patient identifier to pull data together more precisely. (provider also--but that's another issue)

Julie Maas (EMR Direct): @Denise and @Chris you may be interested in connecting with FAST (FHIR at Scale Taskforce) work on these topics.

Krystal Collier: How do we get more prepared for that Dec 2022 date? This new change is not something discussed that I hear in our public health registry conversations on what will be possible.

Jim Daniel: Krystal - I do think we need to educate ourselves more and start to develop some proofs of concept to explore this.

Steven Lane: @Brett Oliver - Re your earlier comment re KY not accepting eCR, I hear from the CDC/APHL team that they are able to receive this now.

Steven Lane: And Chicago is shifting from their CDA – one off approach to electronic case reporting to using the nationwide eCR solution through APHL.

Krystal Collier: @Jim-I agree with that on so many levels as one way forward to advance our future. So much of what @Hans mentioned about not being engaged early enough is what slows the progress of not just the data is there but how we can put that data into action for our public health surveillance activities.

Carl: BioWatch was the sensor program

Krystal Collier: @Joneigh THANK YOU For that comment and 100% agree

Denise Love: there are hospital discharge reporting systems in almost every state that routinely capture morbidity data which are linkable to environmental and other public health/census data sets.

Krystal Collier: Syndromic Surveillance in NSSP ESSENCE can link ED and Air Quality Data as well.

clem mcdonald 2: Lookl at the data over 70 yo were diiding at rate of 4000 per mont. ( i can send it ).
Arien Malec: Not ending soon -- we have the amazing close of the ISP task force

clem mcdonald 2: Aron mir is a GREAT MC

Steven Lane: Thank you @Aaron Miri for excellent moderation.

Aaron Miri: Thank you everyone but kudos goes to the amazing ONC team. I may be the face on the camera but behind the scenes is a small army of superheroes [sic] that truly, I think are some of the hardest working professionals in the industry. So kudos goes to them.

Linda Thomas-Hemak: Wow! What a wrapup.............. These unifying standards are awesome and planned emergence through [sic] an evolution and overlay on EMR MU platform is very exciting.

Joel R Greenspan: Will there be an archive [sic] of this meeting for future reference?

Chris Baumgartner: Any thoughts on NDC vs. RxNorm for PDMP Query? PDMP mostly uses NCPDP and they rely on NDC not RxNorm.

Chris Harrison: Thank you to the organizers for the chance to participate today. Vital Records and Vital Statistics are newcomers to FHIR interoperability, but we look forward to continuing to learn and expand our capacity in this area

Mike Berry (ONC): The presentation material, video, meeting notes, bios, etc. will be available on the HITAC calendar on HealthIT.gov at this link: https://www.healthit.gov/hitac/events/health-it-advisory-committee-34

Julie Maas (EMR Direct): +1 @Aaron. Thank you so much for your service, ONC team!

Linda Thomas-Hemak: The ICD harmony initiative [sic] to drive both clinical care, research and administrative [sic] work will activate a very generative platform for Community Based Participatory Research which is and will continue to be a major engine of Beyond Flexner clinical delivery learning systems aiming to address our primary care shortages and misdistribution and to improve public health, while effectively addressing structural and functional health and healthcare access disparities.

Chris Baumgartner: Will Race and Ethnicity in the USCDI have broader categories than the CDC PHINVADS? Our State Board of Health just adopted [sic] broader categories - https://sboh.wa.gov/Rulemaking/CurrentRulesandActivity/NotifiableConditions

Arien Malec: PHINVADS is the coding standard for USCDI.

Arien Malec: But it's pretty fine grained -- I'd recommend working with CDC to add codes if there's anything missing.

Steven Lane: Occupation has NOT been submitted to the ONC's ONDEC system https://www.healthit.gov/isa/ONDEC so is not yet in the pipeline for addition to the USCDI. Great opportunity for expanding the discussion as we prepare for the USCDI Version 3 submission cycle beginning in July, 2021 when Version 2 will be published.

Arien Malec: YES!

clem mcdonald 2: LIVD is a specification (soon to be an HL7 spec) that maps the i [sic] IVD
manufacture test codes to LOINC. It was at the heart of all of the covid tests, And tests were presented in the LIVD web site within a few days of the emergency authorization. However many lab system do not know enough, e.g. not the specimen delivered to do the full mapping automatically.

Genny Luensman: @Steven occupation HAS been submitted and is currently at level 1

Steven Lane: @Chris - If ONC needs to refine the USCDI requirements re Race and Ethnicity, this feedback should be submitted at https://www.healthit.gov/isa/uscdi-data/race and https://www.healthit.gov/isa/uscdi-data/ethnicity

Steven Lane: Thanks @Genny! It is under the data class of Work Information as opposed to Patient Demographics where I expected to find it. https://www.healthit.gov/isa/uscdi-data/work-information

Steven Lane: And I see that you were the submitter! Great work. https://www.healthit.gov/isa/uscdi-data/usual-work

Genny Luensman: @Steven- thanks! Happy to answer any further questions.

Steven Lane: @Genny - What can CDC/NIOSH or others do to help advance this important data element from Level 1 to Level 2 where it could be selected for inclusion in a future version of USCDI?

Steven Lane: https://www.healthit.gov/isa/uscdi-data/job

Chris Baumgartner: @ Steven - are there more than 6? This is what I believe a state can report to CDC now - https://phinvads.cdc.gov/vads/ViewValueSet.action?id=67D34BBC-617F-DD11-B38D-00188B398520

Genny Luensman: @Steven- we are working to find organizations to pilot collection and use of teh data. As you might imagine, people were very interested in having the data but could not pilot in the throes of dealing with COVID.

Abby Sears: Genny...let me see if are organizations might pilot occupation...

Steven Lane: Go Abby @ OCHIN!

Abby Sears: oops our not are

Dave Mandelkern: Great work on data harmonization and building standard data models. Another positive impact of this on clinical trials in the US would be to a) promote the use of a common set of control patients, rather than each trial having to create their own controls (thus freeing up more consented patients for active arms of the trial); and b) improve ability of trials to integrate data from multiple sites, allowing the trial to more easily move and track the spread of the pandemic geographically. This was discussed in more detail in one chapter of the MDEpiNet Pandemic Response Emergency Prepaedness [sic] Taskforce(PREPT) whitepaper.

Genny Luensman: @Abby- that sounds great.

Mike Berry (ONC): We will open up the line for public comment soon. To make a comment please call:1-877-407-7192 (once connected, press “*1” to speak).
Aaron Miri: @arien - only 3 portals? That's actually pretty streamlined ;-)  

Sheryl Turney 2: thank you! I agree  

Arien Malec: I didn't meanion [sic] the other one that has more limited data, then there's the pharmacy data, the payer data, etc.  

clem mcdonald 2: Need to define the what we mean by procedure. HL7 excluded diagnostic procedures from the procedsur resourc. [sic] Whivch [sic] is intended for process that "invade' the patient in som eway. [sic]  

Linda Thomas-Hemak: Aaron, you have indeed won the MC of the decade award! Keeping this whole day on track and on time was truly herculean!  

Aaron Miri: @linda - Sparkling water. Seriously, its unicorn tears and keeps you going.  

Aaron Miri: :-)

Steven Lane: @Arien & David - Let's plan a time for ISPTF to present to the USCDI TF when we kick off our Phase 3 work after our July TF presentations to HITAC.  

Sheryl Turney 2: I agree Aaron you have done a really fabulous job with the moderation today  

Sheryl Turney 2: Steven good Idea  

Steven Lane: *June presentations  

Arien Malec: Agree @Steven.  

Steven Lane: Ventilator settings would never make it to USCDI based on the current prioritization criteria, which require that the data be applicable to the majority of patients/stakeholders. The USCDI taskforce will be making recommendations to support the potential inclusion in USCDI of high priority data that may apply to more focused populations/stakeholders.  

Sheryl Turney 2: Arien would the ID card standards that CARIN is working on be in scope for ISP?  

clem mcdonald 2: PS i think PCORNET is great. I work with them/ THEy h aveg [sic] assidiously [sic] coded the variables - a differenc [sic] with Sentina. [sic] Of course COMOP did the same  

Sheryl Turney 2: these are the digital health id card standards I am speaking of  

**FINAL REMARKS**  

Mike reminded members that the next meeting of the HITAC will take place on June 9, 2021, and noted that all meeting materials would be made available at https://www.healthit.gov/hitac/events/health-it-advisory-committee-34
Denise and Aaron thanked the presenters for their thoughtful comments and participation and ONC and Accel for their support. Denise thanked Aaron for facilitating the meeting, and Aaron thanked everyone who has and is working on the frontlines of the pandemic for their efforts.

**ADJOURN**

The meeting was adjourned at 5:00 p.m. ET.