

# Public Health Data Systems Task Force 2021 Recommendations

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# **Task Force Recommendations and Report**

- Charges
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# Health IT Advisory Committee (HITAC) Public Health Data Systems (PHDS) Task Force 2021

Charge – This Task Force will inform HHS's response to President Biden's Executive Order on Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats.

#### The PHDS Task Force shall:

- Identify and prioritize policy and technical gaps associated with the effectiveness, interoperability, and connectivity of information systems relevant to public health. This would include a focus on surveillance systems, infrastructure improvements, health equity, clinical engagement, research and innovation, educating and empowering individuals.
- 2. Identify characteristics of an optimal future state for information systems relevant to public health and their use.



# **Updated Task Force Scope**

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



# **Public Health Data Systems Task Force Roster**

Name	Organization
Janet Hamilton (Co-Chair)	Council of State and Territorial Epidemiologists
Carolyn Petersen (Co-Chair)	Individual
Danielle Brooks	AmeriHealth Caritas
Denise Chrysler	Network for Public Health Law
Jim Daniel	Amazon Web Services
Steve Eichner	Texas Department of State Health Services
Claudia Grossmann	Patient-Centered Outcomes Research Institute
Steve Hinrichs	Individual
Jim Jirjis	HCA Healthcare
John Kansky	Indiana Health Information Exchange
Bryant Karras	Washington State Department of Health
Steven Lane	Sutter Health

Name	Organization
Nell Lapres	Epic
Les Lenert	Medical University of South Carolina
Denise Love	National Committee on Vital and Health Statistics
Arien Malec	Change Healthcare
Clem McDonald	National Library of Medicine
Aaron Miri	The University of Texas at Austin, Dell Medical School and UT Health Austin
Larry Mole	Veterans Health Administration
Abby Sears	OCHIN
Sheryl Turney	Anthem, Inc.





# Recommendations



# **Cross-Cutting Recommendations**

#### PHDS-TF-2021\_Recommendation 01

ONC should work with federal partners to create a preparedness plan and data standards for collecting information from within the health ecosystem during public health (PH) emergencies.

#### PHDS-TF-2021\_Recommendation 02

ONC should work with federal partners to create a health data ecosystem that fully supports PH during a response to high consequence PH threats. The plan should create a healthcare paradigm shift where PH is a full partner and integral part of the healthcare ecosystem.



# **Cross-Cutting Recommendations cont.**

#### PHDS-TF-2021\_Recommendation 03

ONC should explore and support the development of additional data standards and classes for PH purposes [e.g. work with the community to prioritize the adoption of new United States Core Data for Interoperability (USCDI) data standards to consistently support and enhance reporting requirements necessary for PH activities].

#### PHDS-TF-2021\_Recommendation 04

ONC should work with the Centers for Medicare and Medicare Services (CMS) and other HHS partners to determine approaches to invest in improving interoperability for healthcare partners that were not part of the Meaningful Use (MU) and Promoting Interoperability (PI) programs to promote the adoption of Healthcare IT standards and secure data exchange with PH. The use of Health Information Exchanges (HIEs) to support data exchange should also be supported (e.g. pharmacies, laboratories, emergency medical services/fire departments).



# **Cross-Cutting Recommendations cont.**

#### PHDS-TF-2021 Recommendation 05

ONC should encourage HHS to continue supporting data modernization initiatives and opportunities for STLTs to share knowledge and experience through workshops, conferences, internships/fellowships, and communities of practice.

#### PHDS-TF-2021\_Recommendation 06

ONC should require standardization of address information collection to facilitate interoperability, geolocation, and merging with census and other SDOH data. Projects like ONC's Project US@ may be leveraged; however, appropriate resources must be provided for implementation. To adequately support patient matching, it may be necessary to approach the issue similar to the implementation of the conversion from Social Security numbers to Medicare ID numbers or the conversion from ICD-9 to ICD-10, with a time period for planning and implementation of technology to support the new standard and a specified date at which all entities are expected to have completed technology implementation and conversion of existing data.



# **Laboratory Reporting Recommendations**

#### PHDS-TF-2021\_Recommendation 07

ONC should coordinate with STLTs and federal partners to increase adoption and use of standardized ELR reports. ONC should explore adding a corresponding Health IT certification for lab orders and results to improve and ensure end-to-end data flows between the provider, lab and PH agency.

#### PHDS-TF-2021\_Recommendation 08

ONC should work with CDC, PH entities, support organizations, and health IT vendors to standardize technical capabilities to facilitate laboratory results data collection and sharing to and across STLTs, including CDC and FDA laboratories where applicable. ONC should work with CDC, Council of State and Territorial Epidemiologists (CSTE), and PH agency experts to establish a framework and process for aligning reporting requests and requirements across STLT and federal levels (CDC and FDA laboratories) with adherence to structural validation.



# Laboratory Reporting Recommendations cont.

#### PHDS-TF-2021\_Recommendation 09

ONC should work with CMS to ensure a standardized set of demographic information is both collected and sent from clinical and laboratory systems, to STLT PH in a timely manner through standards adoption. Standardization should be undertaken to ensure consistency (e.g., "Hispanic" consistently categorized as ethnicity or race across data systems) in measurement and promote a true understanding of impact.



# **Case Reporting Recommendations**

#### PHDS-TF-2021\_Recommendation 10

ONC should advance the adoption of eICR and eCR by providers and PH.

- a. ONC should require the eICR and eCR specific standards, including bi-directional communications between providers, other entities (e.g., payors), and PH within Health IT certification programs.
- b. ONC should encourage CMS to explore making eICR and eCR utilization a Condition of Participation for hospitals, relevant non-hospital-based providers, and other entities.
- c. ONC should ensure that certification programs support the use of eICR and eCR with specific standards for exchange through external providers, such as HIEs.



# **Case Reporting Recommendations cont.**

#### PHDS-TF-2021\_Recommendation 11

ONC should coordinate with CDC, Assistant Secretary for Preparedness and Response (ASPR), and HHS in working with STLTs to align reporting and notifications requirements at federal and STLT levels to avoid duplicative requests or failure to meet surveillance goals. Every effort should be made to align and reduce redundant reporting requirements across federal entities. Processes should ensure necessary data are available in a timely manner at the STLT level for immediate PH action. STLT-level infrastructure and reporting frameworks should be leveraged whenever possible. Specifically, ONC should:

a. Collaborate with CDC, CSTE, the Trusted Exchange Framework and Common Agreement (TEFCA) Recognized Coordinating Entity (RCE), APHL and STLTs to support tools to facilitate and develop standards for automated interjurisdictional routing of case and/or exposure notifications.



#### **Immunizations Recommendations**

#### PHDS-TF-2021\_Recommendation 12

ONC should work with CDC and STLTs to advance the further development and adoption of the HL7 Implementation Guide by both provider systems and PH agencies to meet current and future immunization data needs.

- a. ONC should collaborate with partners within HHS to explore federal policy levers such as Condition of Participation to require providers to transmit data electronically and in HL7 format to the appropriate data receiver. Provider systems shall also be designed to capture all CDC required data elements for IIS.
- b. ONC should also work with partners within HHS and with STLTs to develop a national implementation plan for the roll-out of standards. Implementation support should be provided to STLTs.



#### Immunizations Recommendations cont.

#### PHDS-TF-2021\_Recommendation 13

ONC should collaborate with CDC, vendors, and PH jurisdictions to develop standards and implement infrastructure supporting:

- a. Standards for provider-initiated multi-jurisdictional queries.
- b. Standards for enabling consumer access to IIS data.
- c. Cross jurisdictional exchange of IIS data through immunization gateway and standard Application Programming Interface (APIs).
- d. Connections to the CDC immunization gateway.



#### Immunizations Recommendations cont.

#### PHDS-TF-2021\_Recommendation 14

ONC should work with Office for Civil Rights (OCR) to provide STLT-specific guidance to immunization registries to enable authorized access to minors' records, clarifying what parent/guardian has legal access to a minor's medical record. ONC should also work with OCR to require enablement of consumer access to their immunization data. ONC should support the development of technology to identify who is authorized to access minors' records.

#### PHDS-TF-2021 Recommendation 15

ONC should work with CDC, industry associations, and STLTs to identify a prioritized set of immunization data elements for providers to collect and report to PH.



#### Immunizations Recommendations cont.

#### PHDS-TF-2021\_Recommendation 16

ONC should work with CDC, STLTs, and industry associations to define a minimum set of IIS functional standards. Standards should include the ability to receive immunization data in agreed-upon formats, accept messages using a standard transport mechanism, error reporting, scalable infrastructure, quality patient matching, and patient access to data. The use of a set of criteria that PH systems are measured against should be established. If a system fails to meet expected performance standards, the jurisdiction will be encouraged to correct deficiencies.

#### PHDS-TF-2021 Recommendation 17

ONC should work with CDC and legal organizations (Network for Public Health Law) to identify policies that are limiting or preventing health departments from exchanging immunization data with other systems and organizations across the health ecosystem, including internal organizational limitations from within PH (e.g. disease reporting systems and vital statistics systems).



# **Syndromic Surveillance Recommendations**

#### PHDS-TF-2021 Recommendation 18

Syndromic Surveillance: ONC should collaborate with CDC and STLT health departments to further explore traditional and non-traditional data sources and surrogate markers that could be leveraged to assist in the identification of early clusters/outbreaks of disease incidence or provide additional inputs as an event unfolds. This approach will support several goals:

- a. Provide real-time access to healthcare data, when possible, including all outpatient healthcare providers and inpatient data.
- b. Support the "uncoded syndrome" that SS has become (e.g., via evolution of HL7 standard) and augmentation with additional standards that can track PH-related events such as utilization of personal protective equipment and other situational awareness data (see also situational awareness section).



#### **Situational Awareness Data Recommendations**

#### PHDS-TF-2021\_Recommendation 19

ONC should support the development of standards to advance the exchange of situational awareness data. Specifically, ONC should:

- a. Work with CDC, ASPR, CSTE and other industry to identify appropriate elements to include in the USCDI to support reporting of situational awareness data. These data standards may include information available in, or derivable from, other information stored in EHR systems.
- b. Explore the development of other standards, outside of the USCDI, for situational awareness data not included or derived from EHR systems. Information from inventory management, staffing management, equipment repair databases, and other systems should be considered for inclusion.



#### Situational Awareness Data Recommendations cont.

#### PHDS-TF-2021\_Recommendation 20

ONC should coordinate with CDC, ASPR, and STLT health jurisdictions to define what health care status elements are needed during an emergency to support patient movement and resource allocation. ONC should encourage CDC and ASPR to develop preparedness plans specific to data needs and reporting requirements during a high-consequence PH threat. All stakeholders involved should be consulted to define metrics, data definitions, standards, and procedures for triggering enhanced reporting and when enhanced reporting should subside. ONC should work with CDC to specify standard transport mechanisms that PH receiving systems must utilize, and to establish nationally defined metrics.



#### Situational Awareness Data Recommendations cont.

#### PHDS-TF-2021\_Recommendation 21

ONC should coordinate with CDC to support states in establishing infrastructure meeting STLT and federal needs for collecting situational response and PH data and to support identified core PH data system functions. Infrastructure should exist at a level that supports utilization in response to threats of different size and scope, ranging from local to national issues. Information exchange or access should be provided to higher levels of government as needed for the particular incident. Core functionalities include, but are not limited to:

- a. ONC should work with CDC and ASPR to create a unified data collection framework. This framework should support:
  - a. Flexibility to add new types of data and queries as needed during an emergency
  - Receiving, cleansing, deduplication, anonymization, analysis and publishing of health system and PH data
  - Data aggregation across jurisdictions and data sharing with state and local authorities in a timely fashion, rather than duplicative or data feeds that bypass STLT



#### Situational Awareness Data Recommendations cont.

#### PHDS-TF-2021\_Recommendation 22

ONC should coordinate with disaster preparedness and EHR and IT industry experts (such as inventory and staff management) and CDC to identify core functionalities needed within EHR to support all data needs (including inventory and staffing data) necessary to respond to high-consequence PH threats. ONC should coordinate within HHS to identify ways to incentivize the implementation of these functionalities. Core functionalities include, but are not limited to:

- a. Calculation and reporting of core aggregate metrics such as a surge index score (the degree to which demand exceeds capacity under non-emergent settings)
- b. Identification of core PH data fields



#### **Infrastructure Recommendations**

#### PHDS-TF-2021\_Recommendation 23

ONC should define a core standard set of data elements to support patient matching across PH and healthcare systems (to include demographic information). The complete collection and submission of this information to STLTs should be incentivized.

#### PHDS-TF-2021\_Recommendation 24

ONC should encourage use of HIEs, Master Person Index or Master Patient Index (MPIs), Record Locator Services (RLS), and existing data infrastructure to augment information to provide more complete information to PH around race/ethnicity, disability status, SOGI, and other sources. In the absence of a national patient identifier ONC should work with CDC and CSTE to identify, disseminate and fund public health agencies to implement best practices for methods to represent individual persons in and across de-identified datasets for reporting and analysis purposes.



#### Infrastructure Recommendations cont.

#### PHDS-TF-2021\_Recommendation 25

ONC should work with CDC, STLTs, HIEs, the TEFCA RCE, and healthcare providers to continue the utilization and expansion of PH gateways building upon experience developed implementing portal services such as the APHL AIMS Platform for eCR and ELR to avoid duplicative reporting workflows for providers.

#### PHDS-TF-2021\_Recommendation 26

ONC should work with CDC to standardize display of agreed-upon measure and aggregate reporting elements so that HIEs and other stakeholders could build to support that standard.



#### Infrastructure Recommendations cont.

#### PHDS-TF-2021\_Recommendation 27

ONC should encourage CDC and other HHS partners to support the use of the Patient Unified Lookup System for Emergencies (PULSE), an ONC-supported tool that has been deployed in several states to support case investigations by PH departments for the collection by investigators requiring additional identified, individual-level data. PULSE uses existing data frameworks and connectivity.



#### Infrastructure Recommendations cont.

#### PHDS-TF-2021\_Recommendation 28

ONC should collaborate with CDC, STLTs, and healthcare partners, including volunteer organizations, to assess the needs for and support the development of certified technology to use during preparation and response to PH emergencies. Technology should be available to deploy at the STLT level and should support the following functionality:

- a. System(s) should be single sign-on compatible for system users, should be able to be interoperable with the national interoperability framework, store and maintain medical records, and should conform to minimum functional standards for collecting and reporting relevant data to PH (i.e. ELR, eCR, IIS, SS)
- b. System(s) must also maintain appropriate audit records



#### PHDS-TF-2021\_Recommendation 29

ONC should collaborate with CDC to educate Congress on the need to authorize and appropriate robust, sustained, and consistent funding through CDC to support development and maintenance of PH data systems and PH workforce capable of supporting both routine and large-scale responses. Investments and sustainment needs must be at the level similar to those made for healthcare as seen in the Health Information Technology for Economic and Clinical Health (HITECH) ACT and bring PH to a healthcare-PH data trading/exchange partnership. Funds should be allocated using a comprehensive approach that supports robust, scalable data collection systems and technology in traditionally under-resourced areas. Realization of these objectives will require significant investment from Congress to be successful.



#### PHDS-TF-2021\_Recommendation 30

ONC should collaborate with CDC to educate Congress on the need to support robust, sustained, consistent funding through CDC's Data Modernization Initiative (DMI) to support the enterprise five key pillars and scalability during a response: eCR, National Notifiable Diseases Surveillance System (NNDSS), laboratory (ELR, LIMS and eTOR), vital records, and SS and the PH workforce at the STLT level including technical support from national PH partner organizations.



#### PHDS-TF-2021\_Recommendation 31

ONC should collaborate with CDC to encourage allocation of funding towards developing disease-agnostic infrastructure within public health departments that can support common functions across PH program areas (e.g., centralized user management, single sign on, eCR and ELR infrastructure that supports all reportable conditions, streamline submission of disease/condition data to CDC, etc.) to improve overall efficiency of PH activities and interoperability, and to minimize siloed disease-specific investments in resources while improving infrastructure necessary for scalability.



#### PHDS-TF-2021 Recommendation 32

ONC should work across HHS to create better opportunities to leverage Medicaid, Medicare, and other department funding to support PH initiatives, including reviewing cost allocation strategies. Costs to individuals vs. costs to society should be balanced.

#### PHDS-TF-2021\_Recommendation 33

ONC should collaborate with CDC to create a PH data workforce staffing and execution plan. This would address funding and training needs at the federal and STLT levels, including securing and executing direct hiring authority, exploring ways to shorten the time to hire for data scientists, extending non-competitive conversion to permanent employees for internship and fellowship programs, student loan repayment, internships, fellowships, and training for the existing PH workforce.



#### PHDS-TF-2021 Recommendation 34

ONC should encourage HIEs to adopt funding sustainability models to ensure PH capability development that serves multiple PH goals separately from disease-specific needs, as well as encourage PH use of HIEs where available and affordable. A minimum functional standard for PH support that focuses on not only interoperability and standards adoption, but also infrastructure expectations to improve rapid scalability during a response, should be developed. HIEs should support PH needs rather than define PH needs and augment data feeds rather than replace where existing capacity and functionality are meeting public health needs.

#### PHDS-TF-2021\_Recommendation 35

ONC should collaborate with CDC to encourage incorporation of equity considerations into funding models for public health data systems, including specific and direct investment in traditionally under-resourced communities.



#### PHDS-TF-2021 Recommendation 36

ONC should collaborate with CDC and CMS to invest in education campaigns to enhance knowledge and identify opportunities to incentivize professional development to support PH surveillance. Resources should also be made available to educate the public on the use and privacy rights of information, to enhance trust.



# **Policy Recommendations**

#### PHDS-TF-2021\_Recommendation 37

ONC should collaborate with CDC and OCR to develop and release best practices/guidance for applying the Health Insurance Portability and Accountability Act (HIPAA) Minimum Necessary standard to information sharing with PH authorities. This guidance should be aligned with TEFCA to allow national networks and HIEs to serve as PH intermediaries with the constraint that the uses of data provided for PH purposes be communicated to those whose data are collected.

#### PHDS-TF-2021\_Recommendation 38

ONC should incorporate PH specific components into TEFCA to:

a. Ensure that PH is an authorized purpose of use under TEFCA



# Policy Recommendations cont.

#### PHDS-TF-2021\_Recommendation 39

ONC should collaborate with CDC to support policies that facilitate data sharing without data use for discriminatory purposes and ensure the appropriate level of access is provided to each level (i.e., STLT, federal) of PH authority. Such policies should also ensure that secondary data use by other government agencies and partnerships comply with policies related to informed consent and other protections for patients/individuals (where applicable).

#### PHDS-TF-2021\_Recommendation 40

ONC should collaborate with CDC, CMS, and other partners to explore policy levers to:

- a. Support STLT use of systems that comply with federal standards for interoperability.
- b. Incentivize the reporting of situational data by hospitals and other relevant entities.



# Policy Recommendations cont.

#### PHDS-TF-2021\_Recommendation 41

ONC should collaborate with CDC to identify a PH task force or workgroup (with adequate authority and diverse representation) to address additional interoperability, connectivity, and information system needs relevant to PH and ensure equitable PH response. ONC should collaborate with CDC to evaluate use of existing advisory committees, task forces or workgroups to leverage for this purpose to minimize burden on PH officials. If necessary, a new workgroup should be established.

#### PHDS-TF-2021\_Recommendation 42

ONC should collaborate with CDC to evaluate federal policy barriers that prevent and/or impact PH reporting through HIEs. ONC should collaborate with CDC and other relevant partners to analyze and publish guidance aimed at educating STLT about state-level policy and/or other barriers that prevent or impact PH reporting through HIEs.



# Policy Recommendations cont.

#### PHDS-TF-2021 Recommendation 43

ONC should work with relevant HHS partners to support, subject to existing privacy and confidentiality regulations, payor access where appropriate to PH reporting data to facilitate maintenance of complete patient health histories and clinical data sharing.

#### PHDS-TF-2021\_Recommendation 44

ONC should work with CDC to establish a co-led certification body for PH data standards with funding and participation from STLTs.

a. ONC should work with CDC and industry associations [i.e. AIMS, American Immunization Registry Association (AIRA)]. to establish a certification process to bring all IIS to a defined minimum functional standard. The certification should focus on testing to ensure adoption and uniform implementation of those standards for data content and structure, transport mechanisms, and infrastructure.



# **Health Equity Recommendations**

#### PHDS-TF-2021\_Recommendation 45

ONC should collaborate with CDC, CSTE and STLTs to ensure consistent collection of agreed upon standards for the following health equity data elements: race, ethnicity, disability condition and resulting impacts, sexual orientation, preferred language, SOGI, and data for SDOH. Standards should be implemented through USCDI or other mechanisms to meet community identification needs, as well as to support updating/use of these data for prioritizing provision of services to advance health equity.

- a. ONC should advance the development of national data standards for describing disability status (e.g., wheelchair-dependent, oxygen-dependent, requires assistance navigating stairs, limited walking ability, legally blind, legally deaf, hearing aid user, requires accessible transportation). Standards related to disability should also encompass the physical, sensory, and intellectual components of disability. Data are necessary during PH response to inform evacuation, treatment protocols, and other related activities.
- b. ONC should encourage the use of "language of choice" or "preferred language(s)" to improve access and foster the ability to communicate with and be responsive to the needs of individuals during emergency response.



# **Health Equity Recommendations cont.**

#### PHDS-TF-2021 Recommendation 46

ONC should support the development of technology for patient use while waiting in treatment rooms or other private areas to review and update SDOH data. Data collected in this manner should be available to all entities in the health ecosystem serving the individual, as permitted by applicable privacy laws.



#### PHDS-TF-2021\_Recommendation 47

ONC should work with appropriate HHS stakeholders including STLTs to identify methods for providing transparency to individuals regarding the collection and use of their data for PH purposes.

- a. ONC should also work with OCR and CDC to establish more standard privacy guidance, suggesting standard, individual-centric language in messaging. ONC should work with OCR to support the use of plain language in communications related to access and patient privacy and data sharing to facilitate patients' understanding, available in multiple languages.
- b. ONC should ensure that patients can access complete information about where data about them has been shared and for what purposes.



#### PHDS-TF-2021\_Recommendation 48

ONC should explore delivery of relevant PH-related information through APIs, patient portals, mobile device applications, and other digital distribution channels to ensure that such information is available to patients and consumers in the same ways that they access other relevant protected health information and to facilitate the largest impact/reach. ONC should support the use of digital technologies that raise citizens' awareness of the importance of PH and/or facilitate compliance with PH guidance.



#### PHDS-TF-2021 Recommendation 49

ONC should work with other relevant HHS agencies to ensure that patients, family members, and caregivers have access to situational awareness data, including hospital capacity data, to support their healthcare decision-making. ONC should support the development of technologies that leverage alternative data sources (e.g., evacuation data). ONC should work with OCR and CDC to provide the proper framework for patient access to PH data, ensuring alignment with the HIPAA individual right to access.



#### PHDS-TF-2021\_Recommendation 50

ONC should work with health IT developers to ensure patient portals have access to update key pieces of information by the patient (address, race, ethnicity, etc.) so missing data and information can be completed. Plain language should be developed that provides, in multiple languages, education to the patient about the need for these data so they can be empowered to facilitate accurate collection and counting of their data.



#### PHDS-TF-2021\_Recommendation 51

ONC should collaborate with CDC and health IT developers to ensure that PH data systems generate output in formats that can be readily understood and used by bodies at the federal, and STLT level. Leaders at multiple levels of government benefit from access to clear, granular data that support decision-making at all levels and facilitate activities that meet PH needs.

#### PHDS-TF-2021\_Recommendation 52

ONC should support development of tools to screen data systems for bias in algorithms to ensure that decision-making in support of PH needs is equitable.





# **Discussion**