

Public Health Data Systems Task Force 2021 Report to the Health Information Technology Advisory Committee

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Background

CHARGE

On January 21, 2021, President Biden issued the [Executive Order on Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats](#), which tasked the U.S. Department of Health and Human Services (HHS) with reviewing the effectiveness of public health (PH) data systems to support high-consequence PH threats. With the Office of the National Coordinator for Health Information Technology (ONC) and the Centers for Disease Control and Prevention (CDC) leading section 3 of the executive order, the National Coordinator charged the Health Information Technology Advisory Committee (HITAC) to collect inputs and make recommendations for the final report. A list of Task Force members and their affiliations is in Appendix A.

Overarching Charge

The Public Health Data Systems (PHDS) Task Force was charged with developing recommendations to inform HHS's response to President Biden's Executive Order on Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence PH Threats.

Detailed Charge

The specific charge was to provide recommendations on the following:

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

ADDITIONAL BACKGROUND INFORMATION

After the PHDS Task Force was initially charged, the co-chairs recommended to ONC that the scope be consolidated, given the constrained timeline and breadth of these issues. After consulting with CDC and ONC the PHDS Task Force co-chairs narrowed the scope to focus on analyzing the interaction between clinical and PH data systems. The following recommendations therefore center on the challenges, gaps, and ideal future state for data sharing between PH systems and clinical data sources (i.e., electronic health record(s) (EHRs), laboratory systems, immunization information systems (IIS), Syndromic Surveillance (SS), case reporting, vaccine management software, operational, and other relevant data sources).

Given time constraints, the recommendations focused on topics highlighted by the COVID-19 pandemic. The PHDS Task Force recognizes that there are many other important topics within the subject area of high consequence PH threats including but not limited to:

- Research and Innovation to advance PH reporting and information resources
- Integration and utilization of Social Determinants of Health Data
- Coordination and exchange of data with social service providers
- Non-COVID-19-related PH registries and the use of registry data for both population health and individual services
- Vital statistics
- Chronic health issues including obesity and diabetes

- Infant and maternal health and mortality
- Environmental Health
- In-depth technical/standards analyses of specific PH data systems

The PHDS Task Force encourages ONC to explore these topics in further depth in future engagements. The PHDS Task Force would also like to call attention to Appendix B., where preliminary recommendations raised during discussion on these topic areas have been listed. The PHDS Task Force encourages that these topics and preliminary recommendations be considered by ONC for incorporation into future task forces or other areas of engagement with PH.

Introduction

The COVID-19 pandemic that emerged in early 2020 exposed numerous shortcomings in the United States' ability to respond to large-scale public health events and engage efficiently with healthcare institutions, medical professionals, and supporting community-based organizations. Although investments in health information technology have expanded the capabilities of healthcare professionals and organizations and increased interoperability among organizations, the U.S. public health infrastructure has not had similar investments, has been largely left behind and thus has not been able to benefit from these investments to the same degree as has the clinical healthcare system.

The Public Health Data Systems Task Force assembled by the Office of the National Coordinator in April 2021 was tasked with making recommendations to inform the response of the U.S. Department of Health and Human Services to a presidential executive order. The task force was encouraged to think broadly about not only data systems needed to improve public health response, but also technologies, data uses, and other components that would advance the practice of public health and support engagement with other agencies, healthcare organizations, social services, and the community. It was also encouraged to consider how clinical healthcare and the public health system might promote improved health among Americans through some degree of integration.

To address the breadth of issues in the original charge and constrained timelines, the Task Force co-chairs recommended to ONC that the Task Force scope be consolidated. After consultation with CDC and ONC the PHDS Task Force co-chairs narrowed the scope to focus on analyzing the interaction between clinical and PH data systems, with recommendations focused on the challenges, gaps, and ideal future state for data sharing between PH systems and clinical data sources.

This report includes 22 recommendations related to public health data systems infrastructure, syndromic surveillance, laboratory reporting, case reporting, immunizations, situational awareness data, and standards development and adoption. It provides 16 recommendations related to needed policy underlying the development of 21st century public health data systems and funding mechanisms by which these systems can be achieved. It includes 6 recommendations for improving engagement between public health authorities, healthcare organizations and practitioners, individuals, and governing bodies at the federal, state, and local levels. Through 2 recommendations, as well as through guidance within the other sections, this report identifies data systems, data uses, and strategic approaches necessary to address historically under-resourced needs, eliminate health disparities, and advance health equity in the United States. In addition, the report contains 6 recommendations that apply across the spectrum of public health data systems to facilitate a range of key activities.

While HITAC recommendations are typically directed solely at ONC for implementation, the recommendations that follow include requests for ONC to work collaboratively with CDC, CMS, OCR, FDA, and other agencies within HHS to meet the PHDS Task Force charge from ONC, CDC, and the Executive Order Workgroup most effectively.

Overarching Guiding Principle:

The PHDS Task Force approached the work under an overarching guiding principle that a 'new normal' should be defined where PH is a strong partner with healthcare and that, where appropriate, data and resources should be shared. This holistic approach should be applied across the health ecosystem to ensure data are captured, delivered, and exchangeable and equitable across and between public health and healthcare entities, consistent with applicable law.

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 PH emergencies. The plan should enable PH to receive all necessary information while minimizing implementation and maintenance burden on all parties. The plan should also address the need for appropriate technical training of data collectors to support and facilitate information sharing including understanding barriers for data sharing and working together with communities to develop best practices that will encourage public cooperation and submission of necessary data.

PHDS-TF-2021_Recommendation 02 - ONC should work with federal partners to create a health data ecosystem plan that fully supports PH during 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; changes implemented in healthcare should include a PH lens at the outset to ensure individual as well as population health needs are met and met in a manner that ensures health equity issues are captured comprehensively, respectfully, and illuminated by the data.

PHDS-TF-2021_Recommendation 03 - ONC should explore and support the development of additional data standards and classes for PH purposes. Specifically, ONC should:

- a. 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.
- b. Support the development of Implementation or Companion Guides clarifying and specifying standard datasets and value sets for reporting PH data and accompanying testing and certification of information systems for both senders and receivers.
- c. ONC should mimic previous Standards and Interoperability framework (S&I) efforts to advance existing standards and mature others that are in the pipeline [e.g. Situational Awareness for Novel Epidemic Response (SANER)].
- d. Support the development of USCDI companion guides that identify the data classes and elements required to achieve specific PH activities requiring the exchange of data included in the USCDI since many PH activities are likely to involve elements from more than one class. Companion Guides should also be developed for exchange activities conducted for purposes other than PH.
- e. Collaborate with CDC and other PH jurisdictions to work with provider and standards communities to ensure use of standards and implementation guidance that supports collection of *complete* demographic and contact information elements necessary for PH activities (e.g., demographic information, language preference, contact information - street address, phone number).
- f. Collaborate with CDC and other PH entities to develop clinical decision support (CDS) tools that may be shared between jurisdictions. Provide guidance to State, Tribal, Local, and Territorial (STLTs) on how to leverage existing health IT standards to provide CDS to providers.
- g. Expand PH community participation in standards development and testing, ensuring that there is explicit PH representation during the standards development process and explicit state, tribal, local, and territorial (STLT) representation.

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.

- a. Should include systems used by the following healthcare partners with an active role in responding to PH emergencies: pharmacies, laboratories (all types that conduct relevant testing for reportable diseases and conditions), emergency medical services/fire departments [National Emergency Medical Services Information System (NEMESIS)-based systems], Employee Health clinics, Indian Health Services, tribal health care, school-based health centers and clinics, local health departments, nursing homes/skilled nursing facilities, long-term/post-acute care providers, correctional facilities, military and veterans' healthcare systems. Investment should include support for traditionally under-resourced areas to support creation of a PH system able to support health equity and health disparities.
- b. Health Level Seven (HL7) Version 2 (v2.) formatted messages for IIS, Electronic Laboratory Report (ELR), SS, and Electronic Initial Case Report (eICR), Electronic Case Reporting (eCR) [Clinical Document Architecture (CDA) /Fast Healthcare Interoperability Resources (FHIR)] reporting, where appropriate, should be explicitly included as a standard for use until sufficient funding is provided to evolve both PH and providers to FHIR.
- c. ONC should work with CDC, STLTs, and the Food and Drug Administration (FDA) on mandatory reporting requirements to be addressed by test producers as part of FDA authorizations and approvals of diagnostic testing to share results with the individual/proxy, PH, payors, and the individual's health care team.
- d. ONC should work with CDC, CMS, and FDA to develop a mandate for diagnostic test providers/processors to report test results [including for Emergency Use Authorizations (EUAs)] to PH, the ordering provider, and the patient's care team.
- e. ONC should explore expanding certification programs beyond EHRs to other health information systems supporting healthcare partners listed above.
- f. ONC should encourage HHS to issue guidance clarifying that information reporting may be required from a variety of information systems maintained by a wide range of healthcare organizations. ONC should work with CDC to convene partners including STLT to rapidly develop standardized data collection and data definitions during a public health response. Processes for data collection should ensure data needs at the STLT are met and not bypassed.

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 AND CASE REPORTING

Laboratory Reporting

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. Specifically, ONC should:



- a. Add EHR and laboratory information management systems (LIMS) certification criteria for electronic lab orders and results. The process should include measures for both data completeness and timely reporting to PH and align with previous [ISP taskforce recommendations](#). The order process should include the provision of a minimum set of patient demographic and geographic data necessary for patient matching, addressing health disparities, and conducting patient follow up by PH (e.g. race, ethnicity, street address, phone number, etc.).
- b. Work with CMS to certify labs on conformance to standards through Clinical Laboratory Improvement Amendments (CLIA), where appropriate.
- c. Collaborate with CMS to add additional measures to Merit-Based Incentive Payment System (MIPS) for electronic lab ordering and results reporting. Collaborate with CMS and other entities to explore the use of payment levers to ensure a minimum set of specific data elements are reported from the lab to STLT PH, and to explore ways to incorporate lab interoperability and use of laboratory standards [Electronic Test Order and Reporting (eTOR), ELR] into CLIA and/or PI/Accountable Care Organizations (ACO) requirements. Incentives should be provided to ensure reporting of complete and timely data to public health including a minimum set of patient demographic and geographic data necessary for patient matching, addressing health disparities, and conducting patient follow up by PH (e.g. race, ethnicity, street address, phone number, etc.).
- d. Collaborate with CMS, CDC, providers, HIEs, and STLT PH agencies to explore alternative paths for routing laboratory orders and results that leverage HIEs as intermediaries. HIEs and/or other intermediaries could supply missing data, and route the report to PH, the ordering provider, and the individual's primary care team (consistent with STLT law). Specific measures should be developed for HIEs to ensure they are collaborating with and robustly supporting PH and disease/condition reporting. Existing functional data flows between laboratories and public health should not be diverged or interrupted.

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. This needs to occur for initial reporting of results to STLT, interstate exchanges, state-federal data exchange.

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.

- a. ONC should work with industry experts to develop provider and consumer education surrounding the collection and storage of demographic data [e.g. street address, phone number, race/ethnicity data, language preference, sexual orientation, gender identity (SOGI), and disability] within laboratory orders and or results.
- b. ONC should collaborate with CDC to create recommendations promoting automated electronic result submission testing and improved data transmission error reporting so healthcare organizations can validate content and complete ongoing quality assurance and error management of electronic lab data feeds. These methods should be used to hold organizations accountable to validate content after system deployment to ensure message content meets PH's expectations on an ongoing basis even after initial onboarding.





Case Reporting

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.
- d. ONC should support and advance tools like MedMorph, which can be used to trigger subsequent reporting of data from EHRs, enabling PH to receive all required data.
- e. ONC should collaborate with CDC, Association of Public Health Laboratories (APHL), CSTE, EHR and surveillance system vendors, and STLTs to develop a comprehensive strategy to support the implementation of full eICR and eCR for all reportable conditions by STLTs. PH departments should be able to receive full eICR and eCR data into their surveillance systems, improving the efficiency of reporting and relieving the burden of simultaneous manual reporting from providers and PH.
- f. ONC and CDC should work with standards development organizations, STLTs, CSTE, EHRs and HIEs to develop an automated case investigation standard that supports a future state of ongoing synchronization of clinical and PH data to support PH data needs to understand and better characterize emerging infectious diseases both infectious and non-infectious [e.g. E-Cigarette or Vaping Product Use-Associated Lung Injury (EVALI), multistate outbreak of fungal meningitis, etc.].
 - i. Should explore FHIR, HL7v2, and CDA based standards
 - ii. Should support development and implementation of request/retrieve standards and technologies within PH departments to enable PH to query EHRs and HIEs. A minimum capacity should be set for STLT access to individual patient clinical information from EHRs and HIEs via patient look up portals, and for querying including bulk querying of HIEs for additional clinical data on persons with reportable diseases/conditions.
 - iii. ONC should work with the parties listed above to leverage and align work being completed by ongoing external projects (i.e., MedMorph, National Committee on Vital and Health Statistics efforts) where appropriate.
- g. ONC should support the inclusion of necessary PH data in USCDI, in HL7 US Core, and in the certification of specific eCR standards to ensure that critical data are available in consistent quality and reliability to be shared, consumed and processed by PH systems.
- h. ONC should work with CDC, healthcare providers, and STLTs to bring all case reporting to a defined minimum functional standard. There should be a focus on testing to ensure adoption and uniform implementation of those standards for data content and structure, transport mechanisms, and infrastructure.

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, FDA, CSTE, Association of State and Territorial Health Officials (ASTHO), APHL, and STLTs to harmonize reporting requirements, roles, and capabilities across jurisdictions and states, including data elements, timelines for submission, and communication with providers, payers and communities; and, creation of a minimum national standard (where possible) to support a structure that recognizes different events may require different types of responses, involving potentially different responding organizations [e.g. fungal meningitis, EVALI, etc.].
- b. Collaborate with CDC, CSTE, APHL, and STLTs to robustly and sustainably support tools and required infrastructure for ELR, eCR, eICR, and reportability response such as APHL Informatics Messaging Services (AIMS) and the Reportable Conditions Knowledge Management System.
- c. 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

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.

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.
- e. Further development and expansion of work done by United States Digital Service (USDS) on standards for determining vaccine appointments availability and scheduling appointments.
- f. Infrastructure to support the query of IIS systems on a population level basis by health providers to identify patients who have not yet been vaccinated to support targeted outreach. ONC should collaborate with CDC, IIS operators, and STLTs to improve IIS infrastructure to handle large volume queries and/or data requests.

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.

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

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).
- c. Review and potentially update the current messaging standard currently being used, ensuring appropriate equity data are collected and complete.
- d. Establish standards for adherence to timely submission of data to public health (e.g. messages should be sent within 24 hours of the initial patient encounter) and inclusion of complete disposition data.
- e. Support appropriate use of machine learning to SS data to automate detection of threats, including the development and application of tools at local and STLT levels (e.g., through large health systems, HIEs).
- f. Lower the burden and increase the completeness and accuracy of surveillance by leveraging clinical data and reporting automation.
- g. Support broad disaster response, as well as pandemic and other PH events such as use of these systems to monitor the impacts of and respond to natural disasters (e.g., severe heat events, wind storms, and wildfires) and other events (e.g., smoke and fumes inhalation).
- h. Support querying of partner systems for data retrieval (e.g., via FHIR and bulk FHIR).
- i. Include data from medical examiners, coroner, and funeral homes.
- j. Support machine learning with protection against algorithmic bias.

SITUATIONAL AWARENESS DATA

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.
- c. Collaborate with CDC to ensure that FHIR-based standards under development are flexible enough to capture multiple types of resources and data needs. This will allow standards to be utilized for unforeseen data collection needs during high consequence PH threats.

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. Content should be divided into hazard specific needs. The principle of parsimony should be employed - every data element collected should have an explicit and important purpose to reduce burden of data reporting.

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
 - b. Receiving, cleansing, deduplication, anonymization, analysis and publishing of health system and PH data
 - c. 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
- b. Support of access to anonymized data for development of artificial intelligence (AI) tools for diagnosis and treatment by providers and other parties
- c. Support of healthcare provider access to testing, vaccination, and other relevant PH data, including, when appropriate, patient level data and population level data
- d. Computational support to apply advanced decision support techniques such as CDS Hooks, at the point of care, across institutions
- e. Ability to identify and help providers and government address health disparities issues
- f. Provision of data about the numbers and locations of vulnerable individuals in the community who may require assistance in an emergency
- g. Centralized dashboarding

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
- c. Support for the standard transport mechanism to PH



- d. Estimation and publication of routinely updated status data, including both routine and potential short-term surge capacity, availability of ventilators, surplus ventilators, oxygen administration, CT and MRI scanners, personnel, etc.
- e. Severity grading of known cases in the facility and expected length of stay of cases currently under care, and publication of severity-adjusted profiles of activity
- f. Inclusion of demographic data in transmission of laboratory orders and retransmission of results
- g. Response to automated queries for case investigation using FHIR and Bulk FHIR
- h. Forecasting of the likely future status of healthcare entities 48 or 72 hours in advance
- i. Strategy for integrating and/or transporting data from clinical systems outside of the EHR [e.g., bed/resource management, supply chain systems, Human Resource Information System (HRIS)]

INFRASTRUCTURE

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.

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.

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. Using PULSE to access provider records serves as an ongoing test of the PULSE network, serving as a method of ensuring PULSE availability during a disaster event.

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
- c. System(s) should not be used to replace workflows for providers using certified software capable of exchanging data with PH
- d. Governance at the state or lower level is necessary to comply with applicable state laws



FUNDING MECHANISMS

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.

- a. ONC should collaborate with CDC to encourage the investment of cloud-based infrastructure to improve public health infrastructure scalability and performance. Such investment should aim to increase all states' capacity and build on existing data flows to ensure actionable data are received at the STLT.
- b. ONC should collaborate with CDC to encourage development of plans for cross-program funding of technology investments that support integration, enterprise approaches, reuse of technologies, and interoperability across PH information systems and the health ecosystem, including alignment with TEFCA. Blended, cross-cutting infrastructure with minimal siloing by program area that reduces duplication, training requirements, and user burden also should be supported.

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

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
- b. Ensure that clear technical and policy enablement for high-priority PH use cases is addressed under the TEFCA:
 - i. Case reporting (e.g., eCR)
 - ii. Case investigation (e.g., PH use of query infrastructure)
 - iii. ELR (e.g., APHL AIMS)
 - iv. Immunization submission & query/retrieve
- c. Ensure that specialized PH Health Information Organizations (HIOs) (e.g., APHL AIMS, etc.) have certification paths to be Qualified Health Information Networks (QHINs) under TEFCA, even if they address only one TEFCA use case.
- d. Coordinate with OCR, CDC, CSTE, APHL, and other stakeholders to align policy requirements to allow PH to use the TEFCA infrastructure to:
 - i. Ensure that making data available (e.g., for query) to a QHIN for a PH permitted purpose is consistent with the HIPAA authorized use to supply data to a Public Health Authority
 - ii. Clarify minimum necessary requirements under HIPAA for PH use cases to ensure that data requests for PH purposes (e.g., the above use cases) have clear determinations as public health surveillance is a HIPAA exempt function.

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.

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.

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

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.
- c. ONC should collaborate with CDC, STLTs and organizations supporting under-resourced and underrepresented demographic and geographic communities in order to develop data collection standards for demographic data, best practices on gathering key data, and training support in order to improve equity in response to PH threats.
- d. ONC should advance the development of standards for EHRs and HIEs to support the query by PH officials to rapidly identify and update data on the physical locations of populations of persons with disabilities in a region who may require special support during a medical emergency or disaster.
- e. ONC should encourage CDC to identify best practices for the collection of health equity data elements listed above. ONC should collaborate with CDC, EHR vendors, LIMS, CSTE, APHL, and STLTs to identify, and issue guidance on, the appropriate data source(s) for reporting health equity data elements listed above to avoid duplicative documentation requirements.



- f. ONC should work with CDC, the health ecosystem, and Office of Management & Budget (OMB) to explore the full collection of all existing categories of race and ethnicity within the OMB standard included in USCDI.
 - i. ONC should also ensure that data senders and receivers allow for transmission of multiple race/ethnicities. These practices should include recommended language to explain why this information is important for health care providers to collect and how the information will be used.
 - ii. ONC should encourage CDC to work with the community and health ecosystem to develop standard definitions and categorizations for race and ethnicity.
 - iii. ONC should encourage CDC to release guidance clarifying the level of granularity that STLTs can provide while reporting aggregate race and ethnicity data. Guidance should be flexible in recognizing the differing reporting and analysis needs of each STLTs, giving different population groups.
- g. ONC should encourage CDC to work with STLTs to align requirements and leverage USCDI standards, to reduce variation across states for collection of race, ethnicity, and disability data. ONC should ensure that USCDI complies with, or allows for, new STLT requirements around SOGI, race, ethnicity, disability, and preferred language.
- h. ONC should work with PH, CDC, and other entities to ensure that data collected is stored and protected and data privacy protections are well articulated, to reduce the potential for data to be discriminatory. Additional funding may be necessary to support robust data collection systems and technology in traditionally under-resourced areas.
- i. ONC should develop guidelines and practices in ways that ensure community input into the process and reflect the needs and experience of the communities in which practices will be used.
- j. ONC should further explore and support the use of HIEs, connectivity, and data infrastructure to augment information for the health equity data elements listed above for PH, in order to support service planning, implementation, and evaluation.

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.

INDIVIDUAL ENGAGEMENT

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.



Appendix A - Task Force Roster

Name	Organization
Janet Hamilton (Co-Chair)	Council of State and Territorial Epidemiologists (CSTE)
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 (PCORI)
Steven Hinrichs	Individual
Jim Jirgis	HCA Healthcare
John Kansky	Indiana Health Information Exchange
Bryant Thomas Karras	Washington State Department of Health
Steven Lane	Sutter Health
Nell Lapres	Epic
Leslie Lenert	Medical University of South Carolina
Denise Love	Individual
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	Department of Veterans Affairs
Abby Sears	OCHIN
Sheryl Turney	Anthem, Inc.





Appendix B - Other Topics Discussed

The deliberations of the Public Health Data Systems Task Force involved the use of multiple surveys capturing members' perspectives on a range of subjects that the task force ultimately was unable to discuss during scheduled meetings. Although the task force was unable to finalize these considerations as recommendations to the HITAC, they are included here to inform future workgroups or task forces focused on public health data systems.

SDOH DATA

- ONC should work with CDC and OCR to develop a national framework for the collection and meaningful use of SDoH data. Enforcement, incentives, and linkage strategies to cross-fertilize key data sets (and reduce collection burdens)
- ONC should work with CDC and OMH to provide education on the need for demographic/SDoH data and how to appropriately collect data for entry to EHR.
- ONC should work with CDC and OCR to develop a national framework for the collection and meaningful use of standardized SDoH data, starting with those elements included in USCDI. Enforcement, incentives, and linkage strategies to cross-fertilize key data sets (and reduce collection burdens)

PUBLIC HEALTH AND SOCIAL SERVICES DATA

- ONC should work with OCR and others to explore changes to privacy regulations (HIPAA, 42 CFR Part 2, etc.) and promote partnerships and data sharing agreements between PH and social service agencies to allow for the sharing of necessary data, especially in the setting of a PH emergency.
- ONC should work to identify, pilot, and support the adoption of expanded standardized electronic consent capabilities, to ensure consent to share relevant information between PH and social services is easy to obtain and document, absent changes to privacy regulations.
- ONC should collaborate with CDC to encourage PH agencies to work with local social service organizations (e.g., food banks, transit agencies, housing authorities, etc.) and leverage GIS data to better plan and target response efforts, especially during PH emergencies.
- ONC should work with standards development organizations to develop and advance FHIR standards better providing linking PH with access to social service data.
- ONC should explore the expanded use of APIs for data sharing between social services and PH agencies.

NOVEL TREATMENTS

- ONC should support the development of a FHIR compliant, lightweight EHR tool that can be rapidly deployed during a PH emergency. The tool should include functionality to integrate with local hospital and PH systems and be preloaded with templates for field hospitals and other alternative care sites.



- ONC should encourage HHS to identify a national PH body to act as a trusted, independent clearinghouse for information about new interventions during a PH emergency to provide centralized situational awareness from provider systems.
- ONC should support the development of federal standards for FHIR-compliant medical intervention surveys. ONC should support HHS in requiring race, ethnicity, and age questions in every federally funded study.

TEMPORARY POLICIES AND STANDARDS OF CARE

- ONC should work with CDC and industry partners to develop a standardized approach to triggering and displaying new policies of care and standards. In this standard, the PHA should publish, using an appropriate standard, a business rule that the provider/EHR vendor can incorporate into the EHR to provide CDS services that remind the provider of the policy/standard change when the patient's record triggers the standard or new recommended novel treatment (e.g., monoclonal antibodies).
- ONC should explore use of closed-loop referrals leveraging FHIR.
- ONC should encourage CDC to support development and implementation of publishing services for rules, similar to that use for RCKMS. Inclusion of relevant services should be included as conditions of participation. ONC should encourage CMS to incorporate costs for the applying the new standard within EHRs in any provider payment for providing the changed service.
- ONC should work with industry partners to develop nationally standardized templates and implementation guides for collecting data for Crisis Standard of Care (CSC).
- ONC should include the ability to flag patient records associated with a CSC time period or event (e.g., similar to how death certificates issued during emergencies are flagged for later review to determine if there is a causal link between the death and the event).
- ONC should work with NASEMSO to develop and test optimization algorithms for EMS to help first responders decide which hospital to transport the patient to during a PH emergency.



Appendix C - Glossary of Acronyms

Glossary of Acronyms

ACO	Accountable Care Organizations
APHL	Association of Public Health Laboratories
API(s)	Application Programming Interface(s)
ASTHO	Association of State and Territorial Health Officials
AI	Artificial Intelligence
AIMS	APHL Informatics Messaging Services
AIRA	American Immunization Registry Association
ASPR	HHS Assistant Secretary for Preparedness and Response
CDA	HL7 Clinical Document Architecture
CDC	Centers for Disease Control and Prevention
CDS	Clinical Decision Support
CFR	Code of Federal Regulations
CLIA	Clinical Laboratory Improvement Amendments
CMS	Centers for Medicare and Medicare Services
CSC	Crisis Standard of Care
CSTE	Council of State and Territorial Epidemiologists
DMI	Data Modernization Initiative
eCR	Electronic Case Reporting
EHR	Electronic Health Record
eICR	Electronic Initial Case Report
ELR	Electronic Laboratory Report





EMS	Emergency Medical Services
EUA	Emergency Use Authorization
EVALI	E-Cigarette or Vaping Product Use-Associated Lung Injury
eTOR	Electronic Test Order and Reporting
FDA	Food and Drug Administration
FHIR	Fast Healthcare Interoperability Resources
HHS	US Department of Health and Human Services
HIE/HIEs	Health Information Exchange(s)
HIO	Health Information Organizations
HIPAA	Health Insurance Portability and Accountability Act of 1996
HITAC	Health Information Technology Advisory Committee
HITECH	Health Information Technology for Economic and Clinical Health
HL7	Health Level Seven
HRIS	Human Resource Information System
ICD (ICD-9, ICD-10)	International Classification of Diseases
IIS	Immunization Information System
LIMS	Laboratory Information Management System
MIPS	Merit-Based Incentive Payment System
MPI	Master Person Index or Master Patient Index
MU	CMS Meaningful Use Program
NACCHO	National Association of County and City Health Officials
NASEMSO	National Association of State Emergency Medical Services Officials
NEMSIS	National Emergency Medical Services Information System
NNDSS	CDC National Notifiable Diseases Surveillance System





OCR	HHS Office for Civil Rights
OMB	Office of Management & Budget
OMH	HHS Office of Minority Health
ONC	Office of the National Coordinator for Health Information Technology
PH	Public Health
PHDS	Public Health Data Systems
PI	CMS Promoting Interoperability Programs
PULSE	Patient Unified Lookup System for Emergencies
QHIN	TEFCA Qualified Health Information Networks
RCE	TEFCA Recognized Coordinating Entity
RCKMS	Reportable Conditions Knowledge Management System
RLS	Record Locator Services
SANER	Situational Awareness for Novel Epidemic Response
S&I	Standards and Interoperability Framework
SDoH	Social Determinants of Health
SOGI	Sexual Orientation & Gender Identity
SS	Syndromic Surveillance
STLT / STLTs	State, Tribal, Local, and Territorial
TEFCA	Trusted Exchange Framework and Common Agreement
US@	United Specification for Address in Healthcare
USCDI	United States Core Data for Interoperability
USDS	United States Digital Service

