CDC Advisory Committee to the Director (ACD)
Data and Surveillance Workgroup (DSW)

Data and Surveillance Workgroup Report

ADOPTED by ACD VOTE ON November 3, 2022

Contents

Three Priority Areas to Improving Essential Data Exchange between Health Care and Public Health Systems

BLUF: To deliver on a modern, responsive public health data infrastructure and to advance health equity, the Centers for Disease Control and Prevention (CDC) is working collaboratively to implement changes leading to improved data sharing and data exchange with and between state, tribal, local, and territorial (STLT), federal, and health care partners. To achieve that goal, we propose three priority areas: 1) define minimal data necessary for core data sources[1], with an emphasis on data quality, harmonization, and standardization; 2) establish a public health certification program to promote the automated exchange of standardized and high quality data for public health; and 3) implement a strategic approach to data use agreements and frameworks that provide patient protections while also supporting real-time decision-making and response. These are not exhaustive, nor do they intend to address all data sharing uses and needs across public health. Rather, they focus on establishing priority efforts to address data harmonization and system interoperability improvements, particularly focused on core data sources used across all public health jurisdictions for mission critical public health activities.

NOTE: Appendix I provides further background on considerations related to public health systems standards and certification.

Problem To Be Addressed: The existing public health data infrastructure does not meet the nation's needs from federal, STLT, or health system perspectives. Data systems are out-of-date and lack response readiness; data and technology standards are incomplete, inconsistently implemented and lack specificity; and the capacity and interoperability of systems across jurisdictions is widely variable. Further, many public health data flows and infrastructure are not aligned to current health information technology (IT) utilized in healthcare. Some of these systems used currently are inflexible in that customizations are expensive and burdensome to both implement and maintain. There are, however, some jurisdictions that have achieved success in automated and efficient electronic data management, and it will be important to align and advance such approaches more broadly.

In addition, partners who report data often face differing standards and/or minimal data requirements for different jurisdictions and different federal agencies, thereby increasing the cost and complexity of required data reporting and sharing. Both health care entities and public health agencies spend significant human and financial resources to meet reporting requirements and must design complex workflows to address non-harmonized data requests. Jurisdictions are often limited in their ability to efficiently accept data from partners due to limited interoperability with healthcare IT systems' technology, and variation in data element standards, all of which further limit data completeness necessary to address key health and public health concerns. Additionally, a lack of disaggregated data by race, ethnicity, and core sociodemographic characteristics limits the ability of public health partners to address health disparities.

Finally, there are inconsistent practices and approaches to data use agreements (DUAs). Language in DUAs often differs across reportable conditions and/or jurisdictions, further increasing the complexity for both data

---

[1] CDC has identified six core data sources for electronic disclosure: case data, laboratory-based diagnostic testing data, syndromic surveillance/emergency department data, immunization/vaccine administration data, hospital capacity data, and death data/vital statistics.

contributors and for agencies. This leads to variation in what data is required or needed to be shared and how it may be used, hindering the ability for robust, complete, timely and high-quality information available to support national and local situational awareness. The U.S. lacks the overarching strategy, governance model, and consistent provisions for inclusion in DUAs to ensure that, especially in emergencies, data can be shared quickly, while also addressing jurisdictional requirements and privacy concerns.

This memo outlines three key areas for improving data sharing and exchange that the Advisory Committee to the Director (ACD) should consider as recommendations to the CDC: 1) defining minimal data necessary for core public health data sources; 2) establishing standards for public health data systems and implementing a certification program; and 3) establishing a strategic approach and framework to data use agreements between jurisdictions and the CDC. We ask the ACD to consider taking action on the approaches below, as these three areas are critical to the success of the agency and the creation of more agile public health data systems and data exchange practices.

The Data and Surveillance Workgroup of the ACD proposes that the ACD consider a formal endorsement of the approaches outlined below.

1. Define the Minimal Data Necessary for Core Public Health Data Sources

Ensuring access to data for core public health functions is critical for public health authorities to meet their mandates. Although there is variation in the level of data needed across jurisdictions (i.e., federal vs. STLT), there is also a need to ensure harmonization of data elements. Establishing minimal data necessary base standards for general public health activities is key to enabling complete and technically robust data sharing and exchange capabilities. For example, for data acquired from the health care delivery system, regulations promulgated in response to provisions in the 21st Century Cures Act (Cures Act), found at 45 CFR Part 170, mandate accessibility of the US Core Data for Interoperability (USCDI) via standardized application programming interfaces (APIs) (e.g., SMART on FHIR and SMART Bulk FHIR). This prior work in the health care delivery system can be instructive to public health systems. Public health entities can leverage a wide-scale interoperable ecosystem and build on these foundational data elements in two major ways: 1) advocate to add public-health-relevant data elements to subsequent versions of USCDI, encouraging or requiring electronic health record (EHR) vendors to adopt these new versions; and 2) impose additional national-scale regulations, outside of the Cures Act, that promote the inclusion of standardized public health-relevant data in domain-specific activities (i.e., [USCDI "plus"](.)).

More complete and timely data reported to STLTs and to CDC will enable early identification of an emerging threat, such as a disease outbreak; a significant change in a disease or condition, including who is being affected; and how natural or manufactured disasters are affecting the health of the U.S. population. By more fully maintaining situational awareness through core public health data sources, STLT PHAs and the CDC will be better able to quickly detect known and emerging threats and issue timely and precise response decisions and public health recommendations.

STLT health departments play a frontline role in investigating and addressing the essential pieces of disease control and prevention outlined above for their jurisdictions, and CDC plays a pivotal role in supporting STLTs by monitoring, studying, and evaluating disease prevalence and adverse health outcomes across the nation, and based on these activities, provided needed financial and technical assistance. Establishing the minimal data

necessary to inform public health and support interventions at both the STLT and federal levels will create awareness of core data needs, allow improved interoperability across the public health ecosystem. Proactively defining the minimal data necessary will enable readiness to ensure timely and efficient data exchange and may help to improve data completeness. Health equity considerations, such as disaggregation of data by core sociodemographic characteristics, must be at the center of defining minimal data necessary. CDC has identified **six core data sources** for electronic exchange to support public health: **case data (including reporting from health care to PH and national case notification from STLTs to CDC); laboratory-based diagnostic testing data, syndromic surveillance/emergency department data; immunization/vaccine administration data; hospital capacity data; and death data/vital statistics**. Combined, these data sources will provide critical information for situational awareness that are needed to mobilize a timely and effective response. Establishing the minimal data necessary for these core data feeds at both the STLT and Federal levels, and leveraging Health IT data standards, when possible, will promote more efficient data sharing and exchange.

Bottom line: CDC, in consultation with STLT partners, and with input from healthcare and federal agency partners, should develop, publish, and regularly update a list of data elements that constitute the minimal data necessary for disclosure to CDC for public health activities, including response activities, for data derived from the core data sources indicated above. CDC should also work with STLT partners to develop a list of data elements that constitute the range of data necessary for disclosure to STLTs for the same core data sources. In doing so, all efforts should leverage existing health IT data standards, when possible, to make secure data exchange and sharing more efficient, and to harmonize data element standards across jurisdictions. Importantly, this should not be construed as the only data that may be requested by jurisdictions for public health disclosure, but rather to establish a baseline of core data elements.

2. Establish Public Health Data Systems Standards and Certification

Certification is a process that would help to solve some of the foundational problems afflicting public health data infrastructure today. A certification program establishes a consistent foundation of functionality of technology used to support public health needs. A certification process, through a phased approach, can work to ensure that public health data systems and technologies develop and maintain core capabilities and functions including receiving and integrating standardized data from health care organizations. Requirements could include incentivizing automation and standardization in health care data exchange with public health, reducing variability by ensuring that public health can receive data meeting existing standards, or minimal functional criteria that public health data systems must meet, and establishing consistent capabilities to address cybersecurity and privacy concerns. In order to have an impact on simplifying and standardizing the exchange of data between health care and public health, the implementation of a certification program should be aimed at technologies and systems in which there will be greatest positive public health impact in improving data exchange. Certification should be a phased approach that considers implementation challenges, resource needs, and identifies high impact approaches.

Benefits: Certification for public health data systems is likely to provide distinct benefits for public health agencies and officials:

- For procuring systems, establishes a technical baseline for functional interoperability for public health data systems and health IT products

- Reduces complexity in exchanging information across jurisdictional boundaries

- Improves and harmonizes implementation of adopted standards, helping to ensure essential data content and structure are consistent across data systems, jurisdictions, and with healthcare systems across the country

- Improves data quality and completeness

- Streamlines onboarding for external reporters and public health agencies

- Increases interoperability and more seamless data exchange to other jurisdictions and systems, including to CDC

As noted above, certification will not solve all problems currently burdening public health infrastructure. Specifically, certification may not be able to address:

- Design of the user experience for public health officials/other users

- Variance resulting from customization of data systems, standards, or implementation guidance

- Data use agreements and governance

- Variations in STLT public health data laws, regulations and policies that set out requirements for labs/hospitals/providers to report

- Workforce issues, including hiring and retaining technical talent, such as data scientists and data engineers and training existing staff

Funding considerations and approaches need to be evaluated. Funding that would otherwise be used for DMI and for building critical capacity, systems, infrastructure or supporting the workforce should not be allocated or decreased to support the certification program.

Overall, though, certification for public health data systems can provide distinct benefits for federal and STLT public health agencies and officials in ensuring consistent adoption of consensus health IT standards across public health.

Bottom line: CDC, in collaboration with STLT partners and the Office of the National Coordinator for Health Information Technology (ONC), should develop and implement a coordinated phased approach to certification which should start with expanded guidance for public health criteria, moves to requirements, and ultimately advances to certification.

3. Establish Data Use Agreements and Frameworks

A **DUA** is an agreement that sets out roles, responsibilities, and terms with respect to the use, exchange, transfer, sharing, or disclosure of one or more datasets between the agreement parties. Often DUAs are required by applicable law or used where the data is limited or restricted by applicable laws. In other circumstances data may be used and/or shared without a DUA but parties may seek to execute a DUA to mitigate real or perceived risks. **For the purposes of this memo, the focus is primarily regarding DUAs on data flowing in and out of CDC, particularly from and to STLT jurisdictions.**

DUAs take significant time and resources to implement, because federal and local parties are under differing constraints; there is no single framework or rule that can be applied for all data, providers, and recipients. Delays in establishing DUAs and inconsistencies across the agreements hinder federal public health agencies' ability to maintain robust and timely situational awareness. These challenges also hinder the ability for the CDC to share data with STLTs. CDC currently must enter into different DUAs with multiple jurisdictions seeking the same data, which is inefficient and redundant. Significant efforts must be made to overcome these challenges through the creation of more standardized DUAs or more standardized terms that may be used in DUAs.

Bottom line: CDC, in coordination with STLT partners, should establish a proactive approach to DUAs, and streamline the process, seeking to provide language on protecting individual privacy, and addressing other concerns like the use and re-release of data, consistent with laws applicable to each party, respectively. Potential paths forward include an umbrella DUA approach, developing standardized language for core components of DUAs to address common challenges, or incorporating clearer language regarding the sharing of data collected with federal funds through assistance mechanisms (e.g., grants and cooperative agreements). Ideally this approach to DUAs should seek to address state or local requirements. In addition, such DUAs should incorporate the "flow down" provisions of the [Trusted Exchange Framework Common Agreement (TEFCA)](#) that will enable data flows through that developing national network.

Appendix I: Public Health Data System Certification

Approach and Further Background on Certification

CDC and ONC propose **a phased coordinated approach to certification**: start with guidance, move to requirements, and advance to certification.

We suggest the following activities:

- Identify high impact functional areas to prioritize for components within certification

- Identify, in collaboration with STLT, what modules or specific technologies should be certified

- Define key outcomes for public health certification

- Develop a phased approach. supporting STLT public health agencies to achieve minimal capacities. This approach would enable adoption without added burden and provide opportunities to evaluate and improve data systems

- Determine the scope of technology products that will be affected by certification, including those developed and/or supported by CDC

- Create a feedback loop to engage state, territorial, local, and tribal (STLT) public health agencies and CDC programs in developing and updating components within certification

- Determine needs for common tooling to test conformance to certification modules

- Create support materials, training, technical assistance, and staff training opportunities to aid STLTs in technology updates, workflow and process improvements, and implementation

- Leverage policy and funding requirements to promote adoption of the program

- Create a steering committee internally at CDC, with at least one representative from affected divisions and/or programs, and with participation, engagement and collaboration with STLT representatives and practitioners, to provide detailed feedback and recommendations, as well as help lead change management efforts and communication

- Conduct listening sessions and collect feedback from a broader audience, including STLTs and national associations, throughout the development of the certification program

Certification participation is voluntary and apply to **technology products and their functional capabilities,** not to a department or an agency. For example, immunization information systems, syndromic surveillance systems, and cancer registries will have different applicable functionalities and capabilities that may be subject to certification. Immunization registries will need to exchange data bi-directionally with electronic health records (EHR), while cancer registries may need functionality to de-identify or anonymize line-level data. However, all systems may be subject to the components of certification that require standardization, such as the capacity to receive and send data in HL7, including Fast Healthcare Interoperability Resources (FHIR).

Possible First steps: The following functional areas and associated technology products in line with existing certification criteria specific to the transmission of public health data could be considered and prioritized for implementation in a phased approach in collaboration with STLT partners. The certification program should focus on data exchange between health care and public health supported by existing standards as published by Standards Development Organizations such as HL7.

- Receive and ingest immunizations and immunizations queries

  - immunization information systems

- Transmit and receive syndromic surveillance data

  - syndromic surveillance systems, including the National Syndromic Surveillance Program (NSSP)

- Receive electronic case report data

  - case surveillance systems including Maven, EpiTrax, and the National Electronic Disease Surveillance System Base System (NEDSS Base System or NBS), or intermediaries or other applications used by health departments for this purpose

- Receive, ingest, and send standardized laboratory results

  - electronic test orders and results (ETOR, LOI, LRI)

- Receive cancer case data

  - cancer registries

- Share death data/vital statistics with the National Center for Health Statistics (NCHS)

- Share hospital capacity data with the National Healthcare Safety Network (NHSN)

We recognize that there are capabilities needed in public health products and modules that go beyond interaction with EHRs and the functionalities listed above. The planned listening sessions and feedback from stakeholders will help inform CDC of additional capabilities or components that should be in certification.

To improve data sharing and data exchange with federal and state, tribal, local and territorial (STLT) partners – it will be important for the CDC to engage STLT partners and support their participation in existing industry efforts such as the following:

- The Interoperability Standards Advisory (ISA) process represents the model by which the Office of the National Coordinator for Health Information Technology (ONC) will coordinate the identification, assessment, and determination of "recognized" interoperability standards and implementation specifications for industry use to fulfill specific clinical health IT interoperability needs.

- The United States Core Data for Interoperability (USCDI) is a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange. There is also a process to submit new data elements for consideration.

8

- USCDI+ supports the identification and establishment of domain or program-specific datasets that will operate as extensions to the existing USCDI. USCDI+ is a service that ONC will provide to federal partners who have a need to establish, harmonize, and advance the use of interoperable datasets that extend beyond the core data in the USCDI to meet agency-specific programmatic requirements. This approach will allow ONC to better serve its federal partners, assure that extensions are built from the same core USCDI foundation, and foundation and create the opportunity for aligning similar data needs across agency programs.