

Advisory Committee to the Director,
Centers for Disease Control and Prevention (ACD, CDC)
Data and Surveillance Workgroup
Terms of Reference
November 14, 2023

PURPOSE

The current Data and Surveillance (DSW) Workgroup Terms of Reference (TOR) Document that was voted on and approved on May 3, 2022, by the ACD, CDC, no longer aligns with the current challenges of the Centers for Disease Control and Prevention (CDC) Office of Public Health Data, Surveillance and Technology. Therefore, a new TOR document has been developed with new key issues and questions.

This document defines the activities, membership, and administrative requirements associated with the establishment of the Data and Surveillance Workgroup under the Advisory Committee to the Director, Centers for Disease Control and Prevention (ACD, CDC) in the Office of the Director. The Data and Surveillance Workgroup (DSW) is being established to provide work products to the ACD, CDC regarding agency-wide activities related to the scope and implementation of CDC's Data Modernization Initiative (DMI) strategy.

The DSW convenes a balanced group of subject matter experts in public health science and practice; policy development, analysis, and implementation; and surveillance and informatics from jurisdictional government agencies, non-government organizations, academia, and the private sector to work with the ACD, CDC in their development of advice and recommendations to CDC. These recommendations may support the effective execution of CDC's data modernization strategy across the agency, ultimately playing a key role in the agency's work with public health, healthcare, academic and private sector partners and with the promotion of equity. The work of the DSW may result in reports of findings, observations, outcomes, etc. based on the questions below to the ACD, CDC with the intention of enhancing the framing and implementation of CDC's DMI Strategy.

CDC's commitment to data modernization includes, but is not limited to, investments in: 1) data systems that collect, exchange, manage, or analyze data at any level of public health; 2) strategies and capabilities that support implementation of public health data system modernization; 3) policy levers, as legally appropriate, that advance the standardized collection and exchange of data to support a resilient, sustainable response-ready public health enterprise; and 4) multi-sector partnerships that accelerate the improvements in the nation's public health data infrastructure. The DSW's efforts will assist the ACD, CDC in identifying innovative and promising modernization practices and approaches that align with the principal pillars of DMI; as well as opportunities to advance modern, harmonized data policies and practices, consistent with applicable federal law, in support of public health program activities.

BACKGROUND

CDC achieves its mission by relying on [a broad range of data and surveillance capabilities, systems, and resources](#). There are systemic challenges to the effective collection and use of data

for public health purposes in the United States. The agency advances a layered approach to surveillance, using a combination of large, representative data sources with limited or aggregate data with smaller, “high-quality” data sources to create a fuller understanding of epidemiology and disease transmissibility and severity. The COVID-19 pandemic has illustrated the need for modernization, alignment, and integration across the public health and healthcare landscape to improve surveillance capabilities, particularly for high-consequence public health threats such as a novel, easily transmissible pathogen.

Since receiving modernization resources for the first time just before to the start of the pandemic in early 2020, CDC and its state and local partners have advanced [major improvements to COVID-19 data and surveillance capabilities](#) to address and mitigate the challenges intrinsic to the nation’s public health system, including support from the CDC’s DMI. Data informing the COVID-19 response originate from a broad array of sources, including traditional and non-traditional public health and healthcare settings, community and municipal organizations, the private sector, and many different electronic health record systems to better meet the unique data, surveillance, and analytic needs presented by the emergency.

In 2021, CDC published its first [Data Modernization Initiative Strategic Implementation Plan](#). This comprehensive new approach is framed around five critical priorities - Building the Right Foundation, Accelerating Data Into Action, Developing a State-of-the-Art Workforce, Supporting and Extending Partnerships, and Managing Change and Governance. This new modernization strategy is changing collaboration and innovation across CDC, resulting in agency commitment to key objectives as measured by the achievement of related key results. When fully implemented, these priorities, objectives, and key results will propel public health towards a modern, high-speed, networked public health infrastructure that is intended to work for all diseases and conditions and to provide accurate, timely and relevant data necessary to optimize health for all including those who have been historically marginalized and underserved.

Moving forward, CDC and its partners must be prepared to support, operate, and make use of data flows that move unprecedented volumes of information through an ecosystem that accommodates the spectrum of needs among public health, healthcare, and other partners. These data need to be interoperable and accessible across thousands of local, state, territorial, and tribal health departments and with federal agencies.

The central challenge of public health is to take these vast data—delivered at different times, through different channels and intermediaries, and of different quality and completeness—and turn them into useful, actionable information to improve the nation’s response. CDC cannot and should not tackle this challenge alone and will require the valuable insight of those working in the field in public health and healthcare, as well as those in the private sector, to be successful.

DESCRIPTION OF ACTIVITIES

The CDC plays a pivotal role in safeguarding public health by collecting, analyzing, and disseminating critical data. However, a significant challenge faced by the CDC is the proliferation of disparate data reporting systems. Agency wide fragmentation hinders efficient data management, analysis, and timely decision-making. This issue demands attention to streamline and consolidate reporting systems for improved effectiveness and responsiveness, provide stewardship of limited resources, and reduce burden on data actors, including healthcare and

jurisdictional partners. This new TOR is for the DSW to review the scope of systems, factoring in sustainability, burden placed on partners, and potential redundancies, and make recommendations as to whether the Agency should initiate a process to streamline the technical, system and process related aspects across the Agency, and outline criteria that should be included in the process (such as sustainability, redundancies, burden on providers, alignment with Health IT, alignment with OMB directives and executive orders for secure cloud first strategies, etc.).

KEY ISSUES

1. **Fragmented Data Ecosystem:** The CDC currently employs multiple data reporting systems, each designed for specific purposes and programs. This fragmentation leads to inefficiencies in data collection, processing, and analysis, as well as increased administrative overhead.
2. **Data Silos and Redundancies:** Different reporting systems often operate in isolation, creating data silos that inhibit seamless information sharing across departments and programs. Redundant data entry and storage occur due to overlapping functionalities, resulting in wasted resources.
3. **Inconsistent Data Quality and Health IT Standards:** With various reporting systems in place, maintaining consistent data quality and adhering to standardized data collection protocols becomes challenging. Inconsistencies in data quality can impede accurate trend analysis and hinder the CDC's ability to respond effectively to emerging health threats.
4. **Resource Allocation and Sustainability:** The operation and maintenance of multiple reporting systems require significant financial and human resources **and is not a sustainable model.**
5. **Delayed Response to Public Health Emergencies:** The fragmented data reporting landscape may lead to delayed responses during public health emergencies, as critical information might not be readily available or easily accessible.
6. **Integration Challenges with External Partners:** Collaborating with external stakeholders, such as state health departments or international organizations, becomes more complex when disparate reporting systems are involved. Integration difficulties may lead to delays in sharing crucial health information.
7. **High burden:** There are redundant reporting expectations, often for the same or similar data, on partners, including healthcare and jurisdictional partners. This places a high burden on critical partners, with sometimes limited return value.

Questions:

- How can the CDC implement a process to comprehensively assess data reporting systems, aiming to enhance sustainability, alleviate partner burdens, and minimize potential redundancies?
- How can this process effectively streamline the evaluation of technical, system, and procedural aspects within CDC's data reporting systems, while establishing clear criteria for identifying and eliminating redundancies?

These questions will be the focus of the Data and Surveillance Workgroup over the next 12 months, starting November 14, 2023.

Specific activities will include:

- I. Receive ad hoc presentations from the CDC DMI Leadership Team to review the aims, content, and underlying assumptions of the DMI Strategy.
- II. Receive ad hoc presentations on initiatives, both internal and external to CDC, which will impact DMI outcomes, e.g., establishing foundational infrastructure, ensuring data for action, advancing standards-based interoperability across public health and with healthcare, and aligning federal policies and incentives, consistent with applicable laws and regulations, for efficient and effective data collection and exchange.
- III. Participate in sessions that address questions outlined above.
- IV. Invite CDC programs to present DMI and related activities and offer evidence-based approaches, tools, and other information that supports the successful implementation of their data modernization activities.
- V. Review CDC's DMI implementation outcomes, progress, and metrics to provide feedback to the ACD, CDC that will inform potential advice and recommendations regarding strategies for monitoring the successful implementation of DMI as well as methods to assess agency-wide impact of DMI on the ability of CDC to pursue and document achieving data modernization.
- VI. Provide updates to the ACD, CDC at each meeting.

The co-chairs of the DSW in consultation with the ACD, CDC Designated Federal Officer (DFO) and DSW workgroup DFO will monitor the interaction between the workgroup and the agency to ensure there is not undue influence by the agency on the deliberations of the DSW. In addition, products from the workgroup will be presented to the ACD, CDC for consideration, deliberation, and decision-making purposes.

MEMBERSHIP

The DSW will be established under the ACD, CDC and will be co-chaired by two Special Government Employees of the ACD, CDC. The ACD, CDC Designated Federal Officer (DFO) and DSW DFO, in consultation with the ACD chair, and DSW workgroup co-chairs will identify the Workgroup membership and work priorities. The DSW will be comprised of no more than 15 members and will strive to cover the following disciplines of expertise:

- Public health science and practice;

- Public health preparedness and response;
- Public health policy development, analysis, and implementation;
- Public health surveillance and informatics;
- Data analysis, data science, and forecasting;
- Health information technology; and
- Healthcare delivery.

Due to the complexity and variability of information to be gathered, additional external subject matter experts will be invited to provide presentations during workgroup meetings on an ad hoc basis as needed to provide topical expertise. Such additional external subject matter experts will not be members of the DSW and will not participate in any deliberations or voting activities or workgroup discussions.

MEETINGS, ADMINISTRATION, and TIMELINES

1. Administrative Oversight: The Designated Federal Officers (DFO) for the ACD, CDC and the DSW will work with the workgroup co-chairs to arrange meetings, document meeting proceedings, and report to the ACD on workgroup findings.
2. Meeting frequency: The workgroup will meet as often as needed to address specific issues and to draft the summary workgroup report. It is anticipated that there will be at least three meetings, one of which may be in-person.
3. Meeting structure: In addition to the workgroup DFO, at least two ACD members (which may include the workgroup co-chair/s) must be present at each workgroup meeting for a quorum. Meetings will occur via teleconferences with, perhaps, one in-person meeting. An agenda, relevant publications, and background material will be circulated at least a week prior to each meeting.
4. Conflicts of Interests: Non-ACD workgroup members will complete the form Conflict of Interest and Confidentiality Information for Workgroup Members (CDC Form 0.1473) to disclose interests (e.g., employment, special interests, grants, or contracts) that a reasonable person could view as conflicts or potential conflicts of interest with their committee workgroup participation. Members will also disclose any potential conflicts of interest before any meeting. If a workgroup member indicates a potential or actual conflict of interest, the workgroup DFO will advise the member to recuse him/herself from participating in workgroup discussions that implicate such a conflict-of-interest concern.
5. Confidentiality and Disclosure: The discussions of the Workgroup may include information that is unpublished, protected, privileged, or confidential. Information of this nature must not be disseminated, distributed, or copied to persons not authorized to receive such information. When these types of information are being distributed, the person/s presenting will identify the information as such, so all members are duly informed; such written materials shall be clearly marked as such.
6. CDC Staff Involvement: The DSW may seek input from CDC subject matter experts for consultation or informational presentations that contribute to the workgroup's activities.

Such consultation or information presentations by CDC staff will be transparent and evident to minimize the risk of, or the appearance of, undue influence that would compromise the independence of the workgroup. The parent committee and workgroup DFO will ensure that the workgroup activities and work products are appropriate and not unduly influenced by CDC, ATSDR or by any special interest group.

7. Timelines: The workgroup will hold its next teleconference in the second quarter of 2024. The workgroup will provide a progress report to the ACD, CDC no later than May 2024. A final report will be provided no later than November, 2024. The DSW may be asked by the ACD to answer additional questions upon the ACD's review of the report.
8. Subject content: Findings and opinions of the workgroup members will be discussed at workgroup meetings. A summary report of the workgroup's findings will be presented to ACD for consideration for action (discussion, deliberation, and decision).
9. Workgroup Meeting Summaries: Meeting minutes will be created to capture the information gathered during each workgroup meeting and teleconference. A workgroup summary report will be created based on research activities and information gathered during their discussions. The workgroup summary report will be provided to the ACD for consideration and deliberation in a public meeting. The summary report will be part of ACD's official record.

RECORDKEEPING AND REPORTING

The workgroup co-chairs will present meeting summaries and the final work product to the ACD for consideration and for determining recommendations. Approved ACD recommendations will be included in the ACD meeting summary and annual comprehensive review report.