



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

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*Record of the February 23, 2024 Meeting*



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## ACD DSW: Record of the February 23, 2024 Meeting

The Centers for Disease Control and Prevention (CDC) convened a meeting of its Advisory Committee to the Director (ACD) Data and Surveillance Workgroup (DSW) on February 23, 2024 via Zoom for Government. The agenda included: 1) a presentation on the analysis of the national notifiable disease reporting mechanism in Tennessee in 2022; 2) a presentation on the military branch closure model; and 3) an overview of CDC's Strategy for cloud prioritization and system rationalization data reporting systems.

### Welcome, Roll Call, Introductions, & Announcements

**Julie Morita, MD (DSW Co-Chair)** called the meeting to order at 2:00 PM Eastern Time (ET). A table is appended to the end of this document that provides a list of members present, their affiliations, and any conflicts of interest (COIs) identified.

### Analysis of National Notifiable Disease Reporting Mechanisms – Tennessee, 2022

**Mary-Margaret Fill, MD, MPH (Deputy State Epidemiologist, Tennessee)** observed that while she would be describing Tennessee's specific experiences, these are not necessarily unique to Tennessee. She emphasized that the difficulties and redundancies in national notifiable disease reporting have been previously described. In 2015, for example, the Council of State and Territorial Epidemiologists (CSTE) Executive Board issued somewhat of an unprecedented position statement calling for a common data structure for national notifiable diseases. One aspect of this "Call to Action" was to highlight that jurisdictions submit supplementary or duplicative data in a variety of formats and timelines. This has led to tremendous additional burden and represents a serious programmatic and technical flaw in national disease surveillance modernization. The objective of Tennessee's project was to quantify the existing burden and efficiency of national notifiable condition reporting in Tennessee. In order to do this, a representative sample of 11 notifiable communicable diseases was selected for analysis and surveillance epidemiologists were identified in the applicable program areas to understand CDC national reporting requirements.

Assessment of the total number of data sharing mechanisms utilized per condition found that a mean of 3.4 surveillance systems or mechanisms were required per condition for national reporting. This equated to at least 20 different surveillance systems or data sharing mechanisms being utilized. About 80% of conditions at least partially utilized the National Notifiable Disease of Surveillance System (NNDSS), but 100% of conditions require submission of additional data elements through other mechanisms. Some or all aspects of reporting to CDC were manual for about 3/4 of data sharing mechanisms. About 1/3 of conditions required some manual reporting at least weekly. This analysis estimated a mean time burden of at least 2 hours per week per condition, and at least 1 condition had national reporting requirements that necessitated a full-time employee. To illustrate the complexity of reporting processes, Dr. Fill described case studies for 4 of the 11 diseases selected for analysis. She emphasized that in general, no single reporting requirement is overly burdensome. However, the cumulative requirements placed on state, tribal, local, and territorial (STLT) jurisdictions are immense. With this in mind, she closed with the following recommendations to CDC:

1. STLT jurisdictions should effectively and cohesively communicate challenges and priorities in national notifiable disease reporting processes.
2. STLT partner expertise should be comprehensively integrated into national data modernization efforts to the degree possible, and disengagement should be pre-decisional and with a commitment to timely and transparent communication of final decisions and strategic priorities.
3. CDC could reassess their data governance structure to ensure collaborative and de-siloed efforts between the Office of Public Health Data, Surveillance, and Technology (OPHDST) and various centers' subject matter experts (SMEs).

4. Collection and transmission of non-core public health data collected routinely and during public health emergencies should be examined during ongoing modernization activities. It is often the ad hoc requests around cases of public health importance during cluster or outbreak investigations or amidst an urgent public health response that place untenable strain on STLTs.

## Discussion Points

The DSW members raised the following questions, observations, and suggestions:

- This presentation highlights all of the work that must occur before data can be shared (e.g., processing, cleaning, additional information, et cetera). Perhaps there is work in the standards space that could be done to help acquire the data more easily from the provider community.
  - Dr. Fill said that the idea of a public health investigation around reportable or nationally notifiable conditions is important. A lot of data can be obtained from electronic health records (EHRs), electronic case reports, et cetera that would be beneficial in growing the amount of data that public health can easily access and test. In a lot of these cases, calls are made to patients to collect information on the frontline that they never would be able to get from EHRs. For instance, salmonella cases are asked extensive questions about their food history, what animals they have come into contact with, and what water they drank. A clinician cannot and should not be expected to ask that level of detail. This also varies depending upon the condition. Legionella patients are asked about travel, hot tub exposures, aerosol exposures, et cetera. There are very specific case report forms for many reportable conditions that are used when contacting patients to ask them about their experience and what may have put them at risk for contracting a certain disease in order to disrupt transmission and prevent additional people from becoming ill. It is unlikely that the frontline public health worker will ever be replaced, given that they have relationships with the people who reside in their communities, the businesses there, the hospitals, et cetera. There is always room in the standards space to improve the baseline foundational data that public health is receiving from laboratories, but a lot of what STLTs are being asked to send to CDC through supplemental mechanisms is being collected by frontline public health staff and it is variable from condition-to-condition.
  - Dr. Layden emphasized that the Office of Public Health Data, Surveillance, and Technology (OPHDST) recognizes this critical gap that must be corrected. There are multiple reasons why this happened over time for a variety of reasons, such as outdated technology, funding allocations, et cetera. An actionable set of recommendations would benefit CDC in terms of making progress to address these issues. The OPHDST has been assessing the many systems across CDC, the impact that has, and what approaches can be taken to rationalize those systems. Another component is to determine what truly needs to be sent and for what reason. A lot of requests are received for data that are actionable, but some of it is more for research and long-term purposes that may never be used.
- It would be beneficial for the DSW to understand which issues are creating the most unnecessary work from the STLT jurisdiction perspective. Clearly, a lot of information that needs to be collected from that level is critical for investigations but is specific and is not necessarily being requested by CDC. But it would be helpful to know whether jurisdictions are being asked to send data to CDC that do not seem to jurisdictions to have any value.
  - Dr. Fill noted that there is still some duplicity of effort in transmitting information back and forth between forms depending upon the condition. Some of this will be jurisdiction-dependent. Tennessee tends to use CDC case report forms sent out by CDC SMEs rather than creating their own unless there is something particularly unique about a condition for which Tennessee wants to collect information. Redundancy has been exacerbated in terms of urgent public health responses. Having a better system at the ready that could quickly pivot and adapt would be one option, with the recognition that no one ever knows what the next public health threat is going to be. In terms of pain points and where to prioritize, she thinks that states as a whole have not done a good job of

articulating the challenges because programs know what they have to do in terms of sending data to CDC and just make it happen. It is important to look collectively across multiple subject matter areas and programs to quantify the burden at the state level. It has become such a part of normal workflows that states have done a poor job of quantifying and probably have missed things even in their analysis. Ground truthing and understanding all of the various mechanisms across the agency seems like a top priority that needs to be addressed in order to inform the fix.

- The burden on the public workforce also could be reduced significantly by thinking about ways of sharing with healthcare and ways to leverage that.
- It is important to think about not only the case reporting burden of data entry, but also the grant requirement elements of data entry. Grant reporting burden is a major issue for STLTs. Many STLT staff spend a great deal of time duplicate entering either for grant reporting or in cases where the data have been shared one or more times. Other countries have leveraged artificial intelligence (AI) to reduce reporting burden with regard to taxes. Perhaps CDC could leverage AI to do the same from a data entry standpoint.
- Mr. Brennan emphasized that in order to be successful in terms of the Data Modernization Initiative (DMI), CDC must be able to point to all of the pain points and literally be able to draw direct lines to show that they have made them go away.
- These types of pain points get worse during emergency responses since new systems often spring up and there is a need for frequent modification of forms and databases.
- It would be helpful for STLTs to work with CDC to modernize the case notification process, and ensure timely notification—a real pain point during COVID and continuing.
- New York City (NYC) developed forms that incorporated local needs and the CDC questions. It was not always easy, but their system supported it. Some of this is system-dependent.
- Systems are needed that support the completion of "forms" and allow for extraction and sending data without having to interfere with the jurisdictional workflow.
- It would be beneficial to have a process by which CDC could harmonize across all the reporting requirements. When requests continue to be added on top of one another, the human cost is tremendous and continues to add up as well. Strategies are clearly needed to reduce the human burden, but are not likely to be reduced anytime soon given workforce shortages.
  - Dr. Layden noted that that Mr. Bonander would provide details during his presentation about the number of systems and explained that with the establishment of the OPHDST, the goal is to move from a program-led data-driven environment toward an agency-led data-driven environment. While this will be significantly hard work, there are some policy and governance levers that can be used. It will take some time to identify the recommendations, need, purpose, and rationale for what they are doing, and then identify the levers.
  - Dr. Fill added that to some degree, it is never going to be possible to replace the people who work in public health at the local and state levels. However, there are opportunities to limit how much manual work staff have to do in terms of interviews, such as receipt of more complete and timely data from EHRs and laboratories that will help to reduce the number of questions public health is having to ask. If one's race and ethnicity are already known from the EHR, these questions do not have to be asked. There always is going to be an element that has to be done at the local and state levels to understand exposure and risk factors in order to collect the data needed to understand what is driving transmission of a particular disease.
- The major system interfaces and burdens within CDC are known, but there are many hidden burdens such as the Excel spreadsheets that are emailed to program staff that need to be quantified in order to solve the bigger problem.
- There is always going to be a need to collect data, investigate cases, and integrate with laboratory and public health data. There is work ongoing at CSTE in collaboration with CDC to harmonize some critical data classes that span a wide range and include elements such as travel, race, ethnicity, health equity,

social determinants of health (SDOH), sexual orientation or gender identity (SO/GI), pregnancy, et cetera. The goal is to try to identify harmonized data elements that can be used across all diseases. While that is not going to solve every problem, it hopefully will collect an enhanced set of core data elements upon which everyone can agree and exchange. This is an active project in which hundreds of people are engaged weekly from CDC and the jurisdictions involved in that project.

- It has been difficult to get public health critical data elements into the United States Core Data for Interoperability (USCDI) because they are not high priority for clinical care. While clinical care cannot be asked to collect all of the information public health needs, there are some data elements that would be helpful such as pregnancy that could be more structured into EHRs that would be helpful for clinical care and public health. The ability to query for case investigation information also will reduce the need for people in health departments to call providers.
- In the HL7 world, there are other aggregate data initiatives that offer additional help, such as bulk immunization capability, National Healthcare Safety Network (NHSN) Protect-style aggregate counts for hospital capacity. There are standards in the works for that, but CDC's partnership is needed to ensure that those standards move from pilot projects into broad utilization nationwide.
- Mr. Brennan wondered what all of this duplication and time suck is preventing people from doing that they otherwise could be doing, or if there are people who may actually be worried that if the job of pressing the button to send the spreadsheet is removed, their job will be at risk.
  - Dr. Fill said she thought for the most part, people do this in addition to their normal duties. However, the "sky is the limit" in terms of what people could do if some of the more manual efforts could be removed from their roles. They have their hands in a million things at any given time. They often discuss burnout and attrition in public health and how to ensure that staff maintain the joy in the work that they do. It is often through those kinds of projects that they are reminded of why they went into public health. Even being able to mentor and host more fellows, students, and interns can be crucial. Even an extra hour a week can be crucial in terms of freeing up bandwidth.

## Military Branch Closure Model

**Niall Brennan (Senior Advisor to the CDC Director)** described the Base Realignment and Closure (BRAC) Commission was fascinating to him because the military got to rationalize a lot of military locations in the mid-nineties, but nobody could agree on which locations would be rationalized. Therefore, they established an independent commission whose recommendations essentially were binding. To a certain extent, this is highly applicable to Centers for Medicare & Medicaid Services (CMS) data systems, duplication, cloud modernization, and the number of systems that seem to be collecting largely duplicative data within CDC. The idea with the establishment of a Uniform Commission that relied on objective and uniform criteria and transparent deliberations. He thought the DSW fit all of these criteria, and the agency needs some outside advice in order to avoid getting mired into natural human behavioral responses in large, complex organization of "don't take away my system." With that in mind, he invited input on whether the DSW is willing to function as CDC's BRAC.

## Discussion Points

The DSW members raised the following questions, observations, and suggestions:

- There may be some parallels with this in terms of the ACD Laboratory Working Group (LW) that was given a very specific charge to accomplish in terms of evaluating what went wrong during the COVID-19 pandemic and making some specific recommendations. The LW's recommendations were highly impactful and very specific. That role seemed similar to the role Mr. Brennan was asking the DSW to serve in.
  - Dr. Fleming thought this was a good idea, with one caveat that the problem the DSW is being asked to address relates to the natural tension that occur between STLs and their work with CDC. That is somewhat more of a complex dynamic than what the LW was doing. The LW is a good model, but the additional complexity needs to be taken into account.

- Dr. Layden added that within CDC, coming up with a process will be challenging. The demand for data often is generated from a program to the STLTs due to a specific want or need for data. That is where resistance is going to be greatest. Being able to articulate the rationale for why this is so important, tying it to overarching DMI goals, and then identifying criteria or factors that help to inform decisions may take some important thought in terms of a developing a framework to help inform decisions.
- Two suggested principles within which the DSW might think about this as a starting point are that: 1) There is no way in a future world that states and localities should have to be submitting the same data to multiple parts of CDC using different data entry mechanisms that often are manual; and 2) If CDC wants information that states and localities agree is important, it needs to be submitted through a common reporting mechanism so that it has to be reported only once. One of the barriers is that CDC is asking for information that states and counties normally would not be collecting and are now going to have to identify the resources to do it, even though it is not directly benefiting their work. That second tier probably needs a different mechanism for adjudication.
  - This is likely going to require some type of enterprise- or CDC Director-level policy to stop isolated activities.
  - This seems to be Dr. Layden’s role and the time is right at the CDC Office of the Director level, including Dr. Layden, to put into place such mechanisms. A very important element would be that actions could be strengthened by suggestions from the DSW to the ACD so that this could become a recommendation from the ACD to the CDC Director.
  - This does help to define what the role of the DSW can be and it is more concrete and tangible than it has been in the past.
  - It is important to understand that sometimes the White House gets involved and wants data point X. This certainly was true with COVID-19 and is increasingly true. However, data point X is not always easy to collect and/or easy to transmit if there is not a system to transmit it. The extent to which that could be influenced to address this is not clear.
  - Sometimes data are requested that simply do not exist.
  - Expectation-setting is legitimate in terms of what is realistic to hope for, desire, and what actually can be achieved. This is based on relationships and education.
  - It will never be possible to tell policy makers what to do or what not to do, but data systems can be built that are more nimble to ask questions to and more interactive to policy makers can ask more questions and provide new insights that might be missed within public health.

## CDC Strategy for Cloud Prioritization and System Rationalization

**Jason Bonander (Deputy Chief Information Officer, CDC)** reminded everyone that during the last meeting, he discussed governance and types of federal authorities that CDC has. He pointed out that one of the major goals for 2024 is to ensure that all priority data systems are operating in the cloud by November 2024. Given CDC’s aging infrastructure, it is crucial to move that infrastructure into the cloud in order for the agency to be more response-ready in a matter of hours or days as opposed to months. CDC established criteria to identify priority systems that could move to the cloud and be fully operational by November 1, 2024. As a reminder, CDC has roughly 600 systems. Over 250 systems already have been moved to the cloud and some systems are being actively retired when possible. In terms of next steps, CDC is operationalizing and accelerating everything at a rapid cadence internally and will be reporting progress on a weekly basis. At least 25 systems are targeted for retirement. One area that would benefit from DSW input is to think about what criteria could be utilized to reduce the 300 systems that are still in operation that need to be moved or consolidated, many of which represent different facets of public health practice, including data collection and a myriad of post-award grantee performance monitoring systems that all state and local health departments have to submit. It also is critical for CDC to identify a sustainable model for funding this effort.

## Discussion Points

The DSW members raised the following questions, observations, and suggestions:

- It would be beneficial for DSW to better understand funding for CDC data systems.
  - Mr. Bonander indicated that there is no information technology (IT) budget at CDC for developing data systems. Historically, this has been done through appropriated programmatic dollars for which an IT system is in direct support of reducing the burden, mortality, and/or morbidity of X. Funding may come through one-time dollars for public health emergencies (PHEs) such as 911 or COVID-19. He clarified that when he talks about sustainable funding, it is not so much about external influences as it is about having more discipline inside the agency for managing IT and data dollars.
  - Dr. Layden added that there have been traditional program funds for systems with the release of DMI funds beginning in 2019, some of which has been used to support cloud migration and cloud engineering. However, that is not a sustainable model. Migrating the systems to the cloud does not address the 600 systems. In addition to the need to decommission some of these systems, there also is a need and benefit for CDC to do so for sustainability. For CDC to maintain all of those systems and do so in a secure way in the cloud that moves it to an enterprise-wide system, the agency must be cost-efficient and resource-efficient.
  - Mr. Bonander emphasized that they are not promoting this as a cost-savings, but instead focus on improved responses and capabilities. There is a significant amount of money within the CDC system that ought to be redirected to support common systems and platforms. CDC has working capital funds that operate differently than appropriations in that there is much more flexibility within the working capital fund model to minimize potential issues.
  - DSW would like to see CDC working with HHS and the private sector to determine the key population health drivers on cost and health and ways to move that forward. There is a lot of money in that space where people are trying to do this in silos. This is a much bigger conversation, but one that needs to be addressed because funding is an issue. The DSW could develop some interesting recommendations on how to think about that.

## Closing Remarks/Adjournment

**Julie Morita, MD (DSW Co-Chair)** thanked the presenters and indicated that the DSW would work to process the conversation and think about how they could be helpful.

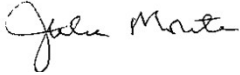
With no further business posed or questions/comments raised, the meeting was officially adjourned at 3:26 PM ET.



## Certification

I hereby certify that, to the best of my knowledge and ability, the foregoing minutes of the February 23, 2024 meeting of the DSW are accurate and complete.

4.3.2024  
Date

  
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Julie Morita, MD (DSW Co-Chair)

## Attachment #1: DSW Attendance and COIs

Name/Main Affiliation	Disclosure of Conflict
Jim Daniel, MPH Amazon Web Services (AWS)	<ul style="list-style-type: none"> <li>• AWS Public Health Leader</li> </ul>
Annie Fine, MD Council of State and Territorial Epidemiologists (CSTE)	<ul style="list-style-type: none"> <li>• No conflicts</li> </ul>
David W. Fleming, MD University of Washington School of Public Health	<ul style="list-style-type: none"> <li>• No conflicts</li> </ul>
Bryant Karras, MD State of Washington, Department of Health, Public Health Laboratories	<ul style="list-style-type: none"> <li>• No conflicts, but he has a small consultancy to Public Health Foundation (PHF).</li> </ul>
Abel Kho, MD, MS, FACMI Center for Health Information Partnerships (CHIP), and Institute for Augmented Intelligence in Medicine (I.AIM)	<ul style="list-style-type: none"> <li>• No conflicts</li> </ul>
Julie Morita, MD (DSW Co-Chair/ACD Member) Robert Wood Johnson Foundation (RWJF)	<ul style="list-style-type: none"> <li>• No conflicts</li> </ul>
Roni Rosenfeld, PhD Carnegie Mellon University	<ul style="list-style-type: none"> <li>• No conflicts</li> </ul>
Valerie Rogers, MPH Healthcare Information and Management Systems Society (HIMSS)	<ul style="list-style-type: none"> <li>• No conflicts</li> </ul>
Nandini Selvam, PhD, MPH IQVIA	<ul style="list-style-type: none"> <li>• No conflicts</li> </ul>
Anne Zink, MD Alaska Department of Health & Social Services	<ul style="list-style-type: none"> <li>• No conflicts</li> </ul>