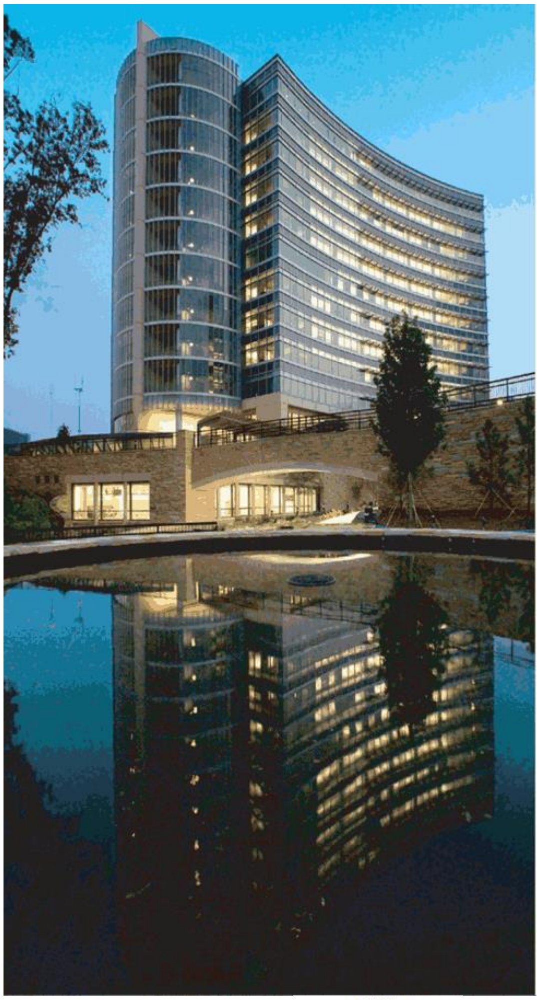

CDC Advisory Committee to the Director (ACD) Data and Surveillance Workgroup (DSW)

Notes from the October 17, 2022 Meeting

Contents

ACD DSW: Record of the October 17, 2022 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 October 17, 2022 via Zoom for Government. The agenda included a review and discussion of a decision memo for the ACD.

Welcome, Roll Call, and Introductions

Julie Morita, MD and Nirav Shah, MD, MPH (DSW Co-Chairs) called the meeting to order at 3:00 PM Eastern Time (ET). A table is appended to the end of this document that provides a list of members present, their affiliations, and conflicts of interest (COIs) identified.

Decision Memo for the ACD

Julie Morita, MD and Nirav Shah, MD, MPH (DSW Co-Chairs) explained the purpose of the decision memo for the ACD titled, "Three Keys to Improving Data Sharing and Exchange: Defining the Minimal Data Necessary for Core Public Health Surveillance Data Sources; Establishing Public Health Data Systems, Standards, and Certification; and Establishing Data Use Agreements and Frameworks" provided to the DSW members prior to the meeting. The goal of this memo, which addresses the DSW's first Term of Reference (TOR), is to take a product forward to the ACD on November 2, 2022 for its full consideration. After taking a few moments for the members to review the document, the DSW engaged in discussions about each of the key issues addressed in the memo.

Discussion Points

Key Issue #1: Define the Minimal Data Necessary for Core Public Health Surveillance Data Sources

- This is a very good and practical idea overall.
- It sounds like a one-and-done. What is needed is a process for deciding what data elements will be needed along the way. It could read similarly to how it reads now, but it should make clear that this needs to be an iterative process over time and that there will be an initial declaration of a minimum dataset that will then evolve.
- A suggestion could be made for CDC to harmonize data elements that are coming in from different data sources (e.g., laboratory data, case data) that can then go back to states such that there is bidirectional movement. In terms of harmonizing, there are 2 aspects: 1) in terms of the de-identified aspect, harmonizing would first be across data elements for consistency and not having multiple programs asking for the same information in different ways with different sources; and 2) regarding the phased approach, ideally there also would be a way to cross-reference identified patient data moving into a longer-term project moving forward.
- Perhaps the word "phased" could be used instead of "iterative." In the beginning, there are likely to be many elements various people will think are essential than will be desirable to try to initially adopt all at once. A phased approach might be a way of allowing for the charting of a roadmap that allows this to grow over time and then perhaps later on iterate. It should not imply that people do not have a good idea about a fairly comprehensive set of data points that are needed, albeit perhaps not feasible to add in all at once at the beginning. The plan from the beginning should be to roll it out in phases and to lay forth the expectation that it is going to grow. There is a policy concern with the initial minimum set being viewed as the only thing that is essential and everything else is nice to have.
- It is critical for CDC programs to harmonize across themselves so that the data requested are simpler and harmonious within itself, which will trickle down to what needs to be collected by the reporting jurisdictions.
- The data streams that are mentioned in this key issue all already have standards/core data elements specified. The more challenging task is reporting to CDC, which has not been specified. Another challenge is the quality and completeness of the data that come from healthcare into public health. CDC has a role to play not only in specifying the data elements, but also identifying policies for those data elements, in

collaboration with Office of the National Coordinator for Health Information Technology (ONC), to improve the quality and completeness of those data.

- In the past, these efforts have been hampered by thinking of a minimum dataset that does not necessarily include the critical information that is needed to investigate cases at the local level. In the past, this has resulted in a hybrid system with fancy electronic reporting for data in which CDC is interested, but then a second and oftentimes paper system to which health departments have had to resort to include the critical information that they need to collect either from sources or by interviewing the case (e.g., contact information in an STD case, whether a child attended daycare and which one, the restaurant at which a food handler works and the history of restaurant inspections there, et cetera). Flexibility and integrative abilities must be incorporated into a minimal dataset so that it aids rather than hinders the actual work that needs to be done at the frontline level when cases are reported.
- It might be worth dividing descriptions into ones for which data are coming directly from the health system and other types of minimum datasets for which data may be coming from a different system, such as health inspector audit histories.
- The second sentence under #1 “More complete and timely data reported to CDC . . .” does not say “for response and/or decision-making” necessarily, but those are going to continue to be true North and would incorporate the concern that this minimal dataset will be used for response—at the local level as well.
- At the local level, almost always identifiers are needed to link data items together. CDC does not want laboratory reports without any clinical information or information from syndromic surveillance. State and local agencies are perfectly able to keep identified information secure and forward only de-identified information to the CDC. However, that linkage needs to occur in order to do the work needed at the local level and provide the CDC the full depth of data that it needs.
- It could be helpful to the CDC for the memo to reflect the 21st Century Cures Act (Cures Act) regulations. For example, the interest is in a minimum dataset above and beyond the US core and how to advance the US core to included what is wanted and how the other mechanisms, the USCDI+, that can be associated with other regulations but that also push electronic health record (EHR) vendors to build those mappings into their products. It is more likely that the suggestions will be implemented than if it is just a statement of desiderata.
- It is very easy to conflate and confuse the data that are being exchanged between healthcare and public health, which is really critical, and the data being exchanged within public health. Key Issue #1 seems to refer to the core data that are being reported to public health, but the word “case” is also included in the language. There are other items besides case data that are shared with CDC by health departments, so this feels “mushed” and in need of clarity.
- It is important to ensure that the memo uses proper terms. Key Issue#1 states that “the CDC will be able to quickly investigate,” but investigations are done by state and local health jurisdictions not by CDC unless a state has specifically asked CDC to assist in an investigation. The primary use case should be described here in terms of what CDC is doing with the data. There are different levels of “minimum.” The document should be clear on minimums for state and local jurisdictions, CDC, and the vendor/provider community.
- It seems appropriate for the DSW to say that CDC should develop minimum standards in consultations with STLT community so that needs are met at all levels of the public health system.
- There are different data for different purposes. There are substantial differences between the data that are exchanged between health care and STLT PH (+/- CDC) and data exchanged by STLT PH and CDC. The issue of what data go directly to CDC is related to data authority policies. Clarifying which is being addressed by #1 it might be easier to understand. Perhaps this should be broken into 2 different components to address what seem to be 2 different workflows, one for minimums for locals and states to be able to respond and one for minimums that CDC needs to study and understand from a larger perspective.
- Most of the HL7 standards mentioned have some of the data elements as optional for states to implement, so there are ways to work within existing standards as long as providers do not perceive “optional” as optional to provide to the state.

- Please consider language cross-sector harmonization (e.g., environmental health data and some chronic disease datasets that support overarching health equity goals as well).
- Dr. Layden pointed out the importance of defining the scope of the use case for the data, given that these suggestions would be given to the ACD and then the CDC director.
- Mr. Auerbach added that the DSW potentially could identify action steps that CDC could take directly that are within its authority and activities CDC could propose in meetings in other venues if those are feasible for CDC to engage in, so that should be clear in the document. Saying that Congress should do “x” would be beyond the DSW’s scope.

Key Issue #2: Establish Public Health Data Systems, Standards, and Certification

- Overall, this is well-written as proposed.
- In terms of benefits in the second bullet and “reduced costs,” this may apply to the entire system, everyone involved in it, and all of the time and effort they put into it. However, state and local health agencies faced with new standards and a need to purchase new systems, there may not be reduced costs—at least in the short-term. Money will be required to invest in this to make it work. If there are reduced costs, return on investments (ROI) is going to take time and it will not necessarily be returned to the state and local health agencies.
- Perhaps “certification will not address” could be changed to “will not necessarily address.” Certification could address elements such as the user interface and the ability of users to consistently draw information in a similar way across the country. Certification itself will not assure that there will be adequate supply chains and vendors ready to support these changes at a reasonable cost across the country and at all of the agencies. There are resource implications and there ought to be some effort by government to subsidize the development of the systems, vendors, and supply chains. Otherwise, the market is going to break down in tiny jurisdictions that cannot afford to buy anything.
- In the absence of resources, this could be fairly onerous and all of it requires time and resources. EHRs, to quality measures, to payment was on a funded trajectory from CMS. While this may be beyond the purview of the DSW, it would be remiss not to acknowledge that this type of work is not necessarily going to reduce costs.
- Perhaps add the word “modularity” under benefits. A lot of Healthcare Information and Management Systems Society (HIMSS) members like to put this forward, given the flexibility it allows health agencies in terms of meeting some of the certification criteria and could be a “carrot.”
- For the last 3 points under “benefits,” perhaps there should be some acknowledgement of the expansion of artificial intelligence (AI) technology and machine learning (ML) as techniques that should be considered moving forward with certification.
- This paper in general deals largely with reporting from the clinical healthcare system in the realm of infectious diseases. Perhaps language should be included at the beginning that outlines that as the primary domain so that the range of people whose data interests do not fall there do not think their interests are being excluded. For instance, it is unclear whether this is about more focused certification for electronic transmission of data from the healthcare system or a broader definition of public health systems. Much of the data and analyses in public health departments have nothing to do with infectious disease reporting.
- Others thought it was too narrow to say that this is just about communicable disease. There are many issues for which there needs to be much more rapid turnaround of information (e.g., cancer, natural disasters, pesticides on watermelon, contaminated nutritional supplements, et cetera) that are not that different from infectious disease outbreaks.
- The intent of the paper must be made clear at the beginning.
- In terms of scoping the certification questions to health systems as divided from other types of data sources, it is important to remember that for the existing certification program that is specified by ONC and executed through CMS payments, the costs did not go to the health systems—costs went to vendors who had to produce certified technology. Home grown systems would be an exception. One aspect of certification that

potentially would reduce costs is that it is much more scalable if data are coming out in the same format from various systems so that they do not have to be remapped and extraordinary efforts are not needed to combine them.

- It would be helpful to infuse the certification section with a strong sense of parsimony so that it does not involve multivariable certification with a high bar. Instead, it should be asking that if the CDC is going to invest funds through grants to states that systems be interoperable with each other a very basic level (e.g., it can produce data on immunization rates at a national level without it being a big data exercise). It might take a couple of years for vendors to catch up, but then public health departments do not have to invent these standards and would have an opportunity to get to scale. This section does not quite capture those goals, and there is a risk that it could be interpreted as a high bar certification with many specifications coming in from multiple well-meaning parties, but when it comes together is a difficult bar to meet.
- There is an ASTHO/CSTE letter that supports the idea of certification that should soon be submitted to the DSW. The letter addresses some of the goals and collective thoughts mentioned in the memo and during the DSW discussion about: 1) the amount of funding something like this would take; 2) the steering committee, which also should include state and local health department representatives in order to set the course so that it will be most effective; and 3) what is getting certified in terms of the pieces of technology, modules, and who they are made by. The items listed as “first steps” are big and are not just first steps. The complexity of what is described should not be underestimated and perhaps should be simplified, starting with small things and then go up. Most health departments do not even necessarily use the systems listed to do the functions that are listed.

Key Issue #3: Establish Data Use Agreements and Frameworks

- As has been done with single Institutional Review Boards (IRBs), the way this should be implemented is first recommending it with a clear data by which it will be required to use a standard data use agreement (DUA), and to give everyone some running time to figure out how to implement it. Realistically, it will not be possible for CDC to enforce this outside of activities they are funding or partially funding, but perhaps this does not need to be said in the memo.
- This section hits on harmonization and bidirectional communication. DUAs are oftentimes the lever that CDC has used to obtain the data they need that often can be harmonized internally to which states legally have access. There needs to be a standardized form that takes into account minimized standards, puts the onus on CDC to standardize data in as many ways as possible, and ensures that it is legal. States sometimes get DUAs that are illegal for them to sign and then get in trouble for not signing them. There must be some acknowledgement to states’ autonomy for data use.
- In terms of accountability and different DUA requirements at state and local levels, the Social Security Administration (SSA) created an authorization for release of records that could apply in every jurisdiction for the context of collecting medical records for disability determinations for Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). The document essentially floated everyone up to a level where one document could satisfy everything. It may or may not be necessary in this context, but it is not impossible to get to a set of standard agreements that would alleviate the problem of each state having to have its own DUA because of uniqueness of state law. Even just narrowing the number of documents could improve the situation.
- Regarding “sticks and carrots,” if there is a standard set of DUAs and institutions covered by the information blocking rules insist on a specialized agreement, an argument could be made that their insistence on agreements above what should be legally required to release data is information blocking. The regulators at HHS might agree with this, so perhaps this could be addressed in the memo.
- Dr. Layden, CDC, indicated that within CDC, a DUA template has been developed that has been provided to some associations for feedback. This DUA has been used in multiple instances and there is standardized language that has been programmed to use in different DUAs. There also is an effort to formulate DUA policy across the agency, but it does not get at the concept of an umbrella DUA or DUA for core data

sources. It is a very generic template with consistent language. There is a precedent for a standardized template and perhaps an opportunity for the DSW to have some input on the evolving DUA policy, and the concept of an umbrella could have benefits.
- While there are certain instances for which a DUA would be needed, a precedent should not be set that there is a need for a DUA that cascades all the way down to providers. There are agreements with Health Information Exchanges (HIEs) that allow states to receive all of the data mentioned in the memo without having to have individual DUAs with all submitting organizations. Whatever goes into a CDC master template DUA should not inadvertently cascade down new requirements to submitters. Similarly with the Trusted Exchange Framework and Common Agreement (TEFCA) and the HIE Common Agreement, an effort needs to be made to determine if/how that template overlaps or will impact those agreements. Perhaps a suggestion could be made by the DSW to the ACD that Sequoia and the National Exchange have not fully embraced the needs of public health in what they are specifying for that exchange. This is a very healthcare-centric model in these HIEs. If public health is going to be part of the healthcare bi-directional exchange community, leverage and assistance is going to be needed from HHS organizations to make the next step of interoperability to happen.
- Two things missing in this document are workforce and finance, which are key to making this work happen and for which there are specific steps CDC could take. Dr. Morita emphasized that this memo is focused on the first TOR. There is a separate TOR that is focused on workforce and sustainability, and a separate TOR that relates to funding, procurement and program implementation. .
- Given that the Health Information Technology Advisory Committee (HITAC) and ONC will be meeting to complete their recommendations in mid-November. It will be somewhat tricky if the DSW makes their suggestions before this. Dr. Shah indicated that Micky Tripathi will be informally read in and will review the memo before the DSW vote.

Action Items/Future Meetings/Adjournment

Action Items

- **Key Item #1**
  - Dr. Mandl will work on the language pertaining to the 21st Century Cures Act beyond USCDI
  - Dr. Karras will cut it into 2 parts instead of 1
  - Drs. Zink and Fine will work on harmonization language
- **Key Item #2**
  - Drs. Zink and Fine will work on draft language pertaining to the ASTHO/CSTE letter
- **Key Item #3**
  - Drs. Mandl and McGraw will work on draft language on DUAs and information blocking
  - Dr. Layden will share the DUA template developed within CDC with the DSW

Future Meetings

- November 2-3, 2022 ACD meeting. The goal is for the DSW to submit items going before the ACD by October 27, 2022. Suggested copy changes should be submitted by no later than COB October 20, 2022.

Adjournment

With no further business posed or questions/comments raised, the meeting was officially adjourned at 4:31 PM ET.

Certification

I hereby certify that, to the best of my knowledge and ability, the foregoing minutes of the October 17, 2022 meeting of the DSW are accurate and complete.

Julie Morita

10/24/2022

Date

Julie Morita, MD (DSW Co-Chair)

Nirav R. Shah

10/24/2022

Date

Nirav R. Shah, MD, MPH (DSW Co-Chair)

Attachment #1: DSW Attendance and COIs

Name/Main Affiliation	Disclosure of Conflict
Jim Daniel, MPH Amazon Web Services (AWS)	• Public Health Leader for AWS
Annie Fine, MD Council of State and Territorial Epidemiologists (CSTE)	• No conflicts
David W. Fleming, MD Clinical Associate Professor University of Washington School of Public Health	• No conflicts
Cristal Gary, MPH (ACD Member) Amita Health	• No conflicts
Lynn Goldman, MD, MS, MPH (ACD Member) George Washington University (GWU)	• No conflicts
Bryant Karras, MD Chief Medical Informatics Officer, Sr. Epidemiologist State of Washington, Department of Health, Public Health Laboratories	• No conflicts
Abel Kho, MD Center for Health Information Partnerships (CHIP) Institute for Augmented Intelligence in Medicine (I.AIM)	• Advisor to Datavant
Kenneth Mandl, MD, MPH Computational Health Informatics Program, Boston Children’s Hospital Harvard Medical School	• Receives funding from CDC
Devin McGraw, JD, LLM, MPH Invitae Corporation	• Receives a salary from and has minority shares in Invitae and is an advisor to Datavant
Rhonda Medows, MD (ACD Member) Population Health Management at Providence	• No conflicts.
Julie Morita, MD (DSW Co-Chair/ACD Member) Robert Wood Johnson Foundation (RWJF)	• No conflicts
Valerie Rogers, MPH Healthcare Information and Management Systems Society (HIMSS)	• No conflicts
Nirav Shah, MD, MPH (DSW Co-Chair/ACD Member) Olea.Health Stanford University	• Kinsa Health and STERIS
Anne Zink, MD Chief Medical Officer for the Alaska Department of Health & Social Services	• No conflicts