HELP Committee Meeting – RE: PREVENT Pandemics Bill
CSTE Talking Points (Day 3 – Winter Executive Board Meeting – 02/16/2022)

- Thank you for taking the time to review our comments and to meet with us; we are excited to see that there is so much interest in trying to address the challenges we faced with public health data during our response to COVID-19.

- We want to continue to work with you to make sure we get this right and are building a system that can be sustained and work for us during a pandemic response AND for our every day public health needs nationally, and across and within all the jurisdictions in the country.

- While our comments on the bill spanned a few different sections, we really want to focus on Section 213 since that is where a number of our questions exist; but we are happy to answer any questions that you all have, and we want to start there.

- Before going to your questions, I want to offer a few opening thoughts from CSTE's perspective and where we are today.

- Right now, public health data reporting is required under state, local, tribal, and territorial law and the requirements are for laboratories, health care providers and others to share reportable data with STLT public health authorities; STLTs then share data with the CDC, most often with certain identifiers removed (including name, address, DOB, phone number).

- STLT laws and regulations vary, but many prohibit sharing of these identifiers with persons who do not require these data for public health purposes.

- Right now, as the system currently exists; CSTE and our members are not comfortable with the idea that CDC would have access to these individual identifiers and many of our comments to PREVENT focused on ensuring these protections for individuals' data

    - Key issues include the protection of patient privacy and the lack of a justification for sharing those data with the federal government
    - (Raise report stream example if anyone asks a question about any identifiable data CDC has right now)

- We understand that part of the goal of this section is to provide CDC with additional authority to collect data directly and we have several concerns:

    - First, about CDC and other federal agencies having certain elements of **identifiable data**;

  - Second, the absence of guardrails around use of any data received by the federal government prior to or simultaneous with a STLT jurisdiction becoming aware of the data or the use of the data;

  - Third, the operational responsibility that would be placed on the federal government to deliver data in a timely and complete fashion as REQUIRED by STLT law so that STLT health departments can meet the needs within their jurisdictions.

- If we can all agree that STLT access to immediate identifiable data is ESSENTIAL for our response to public health threats in and out of a pandemic situation, then we need to work to improve the quality and timeliness of those data moving from health care and other sources to public health (as well as within the public health ecosystem – within health departments and to CDC once health departments have collected additional data and processed the data into usable information) —that is the goal of CDC's data modernization initiative.

- If CDC requires reporting of data from health care providers and other reporters (e.g., laboratories), this presents the very real risk that reporters will prioritize this federal mandate, avoid duplicative reporting, and ONLY report to CDC.

  - There is also a risk that existing and well-functioning data streams will need to be revised to accommodate any new federally mandated reporting streams. This would be DISRUPTIVE to current STLT data systems, some of which are working well and have received investment (albeit not enough) over the past 10-15 years.

- Then, under this hypothetical model in order to ensure STLTs have access to data, it would become CDC's job to share this data with STLTs.

- As it stands right now, CDC does not have the technical infrastructure to collect ALL public health data and ensure that it goes to the right places (i.e. getting data with identifiers (that are REQUIRED for public health response) to STLTs and only pulling down the portion of the data required for CDC needs); to do this, the federal government would be creating a huge new infrastructure—a platform that would need to be developed with STLT needs taken into account while providing immediate data to CDC at the same time; we'd be talking about a massive investment that needs to be done very carefully in consultation with states; we are very far away from that existing (more details below only if needed).

  - In this model, health care providers and other reporters would report into a central data hub (not states, but that data would have to go to states first.

  - CDC would not have complete access to data within that data hub, whatever it is.

  - But it has to be a federal system developed with STLTs needs in place.

- The volume of data will be huge and we need a way to ensure 24/7 operations, responsiveness to STLT needs if there are any data transmission issues (which are inevitable), privacy, protection, and traceability of data use.

- Do we want to use AIMS as an example even though it is not exactly the same, but as the HUB messenger?.

- **This is a big change in how data are currently collected and depending on what the goals are for this legislation and the federal government, we stand ready to work with you to help get to those goals, but we want to be very clear about the precedent this sets and the shift this means for our current federated public health system.**

- (*Pause here for questions from the staff*)

- IF ASKED ABOUT TIMING of data:

  - Data needs to go to STLT first (working on language around sequential here), then it can go immediately or almost immediately to CDC (even if the timing of these is short, ensuring STLT FIRST protects state law and ensures that STLTs are not left out.

  - We are concerned that simultaneous access gives CDC more priority and access over STLTs.

  - There is also a concern about how federal law could mandate reporting at the STLT level, we are still trying to understand this better and would want to work with you on the language ensuring we are not superseding state law without also giving CDC MORE access to this data than STLTs

Other questions:

- What are the overarching goals of this section?
- What data are we TRYING to get to CDC?
- Do we want this data always, or just in pandemic times?