



CSTE

COUNCIL OF STATE AND
TERRITORIAL EPIDEMIOLOGISTS

NSSP REGIONAL DATA SHARING WORKSHOP SERIES

Capstone Workshop Report

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with support from:



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Executive Summary

The Council of State and Territorial Epidemiologists (CSTE), in collaboration with the Centers for Disease Control and Prevention (CDC), concluded the 2019 regional data sharing workshop series with a capstone event highlighting accomplishments and further exploring the utility, legality, and processes for sustaining data sharing among National Syndromic Surveillance Program (NSSP) sites. The capstone event demonstrated the value of data sharing through presentations of regional data sharing activities:

- On-going cross-border opioid surveillance project (South and East outcome);
- Communication toolkit to influence decision makers (Northeast outcome);
- Inter-site data sharing process (West outcome);
- Requirements for a hub-and-spoke data use agreement (DUA) (Midwest outcome).

Routine data sharing for situational awareness will help prepare sites respond to emerging threats and surveillance needs. DUAs are not needed by every site – however, some sites may require one. A master DUA with the NSSP should be generic enough to allow routine data sharing for situational awareness with use case specific addendum. Technology improvements to the NSSP BioSense Platform allow for more granular data sharing by specific data element. Some sites may need to have more limited data sharing per their regulations and law – however, that should not dictate what other sites share.

Successful projects utilizing shared data through the NSSP BioSense Platform should continue to be highlighted in national forums to improve the visibility and value proposition to key stakeholders and decision makers. A policy brief or position statement by member organizations (like CSTE) will help drive adoption by more sites.

The “national view” available through the NSSP BioSense Platform is currently restricted to Health and Human Services (HHS) regions providing limited utility for improved public health impact through surveillance. By increasing the granularity to state or three-digit ZIP code, the NSSP user community will improve the utility of the national surveillance system. The interpretation of that data will be further enhanced by improved metadata of submitting sites’ data.

Background

The National Syndromic Surveillance Program (NSSP) Data Sharing Workshop Series concluded with a National Capstone event at the NSSP grantees closeout meeting following four regional workshops. The Council of State and Territorial Epidemiologists (CSTE), in collaboration with CDC, convened the four data sharing workshops to:

- 1) realize the value of sharing data across jurisdictional boundaries through practical activities, and
- 2) build trust and aspiration with other NSSP BioSense Platform users to foster continued post-workshop data sharing.

The workshops produced demonstrative gains in confidence across all assessed syndromic surveillance skill categories:

1. Sorting and Grouping of Emergency Department (ED) Data
2. Data Analysis and Interpretation
3. Communicating Syndromic Surveillance (SyS) Information
4. Data Quality Assurance
5. Data Sharing
6. Emerging Technologies

In addition to workshop participant confidence increase in performing these essential syndromic surveillance skills, the participants highly valued the ability to work with NSSP BioSense Platform's ESSENCE tool with their colleagues, CDC technical experts, and health scientists. The establishment of new working relationships across the regions reinforced the need to build trust with the people that make-up the national syndromic surveillance community. Sharing real-world data on a live system provided the tangible experience needed to establish projects that can advance data sharing on the NSSP BioSense Platform.

The workshop series produced multiple mini-projects designed to address practical applications of shared data through the NSSP BioSense Platform and existing political barriers. The mini-projects had natural overlap and groupings across the four regions, as illustrated below:

Figure 1. Workshop-series chartered projects.

Use Case	Cross-border Sit. Awareness	Overdose Dashboard	Alert Network	Overdose Dashboard	Model Dashboard	Shared Suicide Data
Legal / Political	Data Sharing Parameters	Process for sharing	DUA Template	Common DUA		
Communication	HELP! (Resources for new users)	Leadership Comms	Comms. Guild			
Interpretation	Data Quality Reports	Data Quality	Data Quality			
Other	CA BioSense Participation					
	South and East	Northeast	West	Midwest		

The Capstone event provided a forum to 1) recap the workshop series for NSSP grantees, workshop participants, and leadership and 2) begin to harmonize the regional projects into national priorities for practical and political solutions.

Importantly, the Capstone event allowed meeting attendees to hear lessons learned regarding new norms for sharing data through the NSSP BioSense Platform that were highlighted during the workshops. Specifically, with regards to the data sharing, the value to state and local public health agencies’ missions is clear – motivation to share data is no longer a barrier. The technology (and competency using it) has advanced significantly as well, allowing for granular data sharing with specific users. However, as data sharing increases, the interpretation of that data will be reliant on high quality representative data with the ability to access metadata of other sites.

Capstone Activity

Following a summary of the workshop series, four mini-projects were highlighted through review their project charters and the applicability of the work for national solutions.

Cross-border analysis of shared data by the North Carolina Department of Health and Human Services identified health seeking behavior of North Carolina residents for opioid overdoses in neighboring states. The syndromic surveillance programs of Tennessee and Virginia shared data with North Carolina through the NSSP BioSense Platform to enable the analysis.

The Leadership Communications Project expanded on their work to establish executive level talking points extolling the importance of data sharing with a focus on attaining leadership buy-in for data sharing approval.

The final two groups to present focused on standardizing a process for agreeing to share data for specific processes with site administration approval and the continued need for some states to have a data use agreement in place to allow data sharing from their state.

With this framing (applied use, communicating the need, standardized process for granting data sharing, and the legal framework to allow it), Capstone participants engaged in a world café activity to explore the following questions:

- 1) **Use:** What are the most compelling or urgent use cases for shared syndromic surveillance data using the NSSP BioSense Platform? For each, what information should be presented to scope and authorize inter-jurisdictional projects (i.e. site to site, site to sub-site, site to CDC program)?
- 2) **Legal:** What issues or topics should an inter-site, all-hazards “master” agreement cover? For nationwide application, what are the conditions for each issue or topic?
- 3) **Political:** What could be a more predictable, common, and responsive process for authorizing syndromic surveillance data sharing to address emerging hazards and public health interests?

The world café model establishes a moderator for the table that maintains continuity as participants cycle through each topic as a group. The moderator expands on the previous conversation with the new group and gets successively further in detail. Following a full cycle through each group, the inputs were consolidated and validated through open discussion. The output from each topic are summarized below.

Use

The utility of data sharing was as varied as perspectives in the room and highlighted typical syndromic surveillance use cases. When scoping these surveillance projects, participants discussed a need to include duration of the project, who would be sharing the data, who would be receiving the data, and for what purpose. Interpretation of the data requires an understanding of data provenance and quality (a reiteration from the workshop series findings).

There was an arc of discovery that emerged when discussing the value proposition of data sharing. Participants agreed that the value of sharing data could be demonstrated in a topical use case (like opioid surveillance); however, normalized regular data sharing would have longer term impact and value. Participants suggested that data sharing should be more regular, allowing for increased familiarity with data and knowledge of trends *prior* to emerging threats.

The workshop series suggested that a specific use case is needed to share data. Capstone participants emphasized that it is more important to build the capacity and relationships to enable the collaboration needed to monitor issues of regional or national significance, rather than on focusing on specific data sharing events (i.e., information sharing over data sharing). Ultimately, the perceived value generated by use cases affects policy decisions and legal options available for data sharing.

Legal

In reaction to workshop series findings that some sites may still need DUAs to actively share data, participants were asked to think about issues or topics that an inter-site, all-hazards, national “master”

Potential Shared Data Use Cases

Outbreak investigations, emerging threats (including vaping related injuries), environmental issues, mass gatherings, seasonal illnesses, drug overdose surveillance, migration (including immigration, displacement, and repatriation) ...

agreement needed to cover. Key elements of a master agreement, as described by the participants, would include:

- Is a Data Use Agreement needed, and who would sign?
- What system(s) is used?
- What is the use case, need, or purpose for sharing?
- Who are the agreeing parties?
- What is the level of access to be given (and with whom)? Who owns the data?
- What is the timeframe and duration for the data sharing agreement?
- How will the data be protected and stored?
- What is the governance process?
- What is the data stewardship plan?

Capstone participants highlighted the importance of addressing protections, assurances, and accountability to enable good stewardship of the data being shared. In case of a data breach, security measures and the steps for notifying the owners of the data should be specified. Assuming the NSSP BioSense Platform is the system through which data is shared should standardize many questions.

Participants provided additional context to be considered for a master data sharing agreement. State laws and regulations (including state reportable condition laws) will need to be considered for a national application and whether syndromic surveillance is included in a site’s reporting mandate. Site-level restrictions may also need to be considered in an agreement, but these should be specific to the affected site and *not* hinder broader sharing.

A conflict in scope was identified during the legal conversations: a more specific agreement may be easier to execute; however, a more generic agreement will allow for the application of routine surveillance. Regardless, the purpose of the agreement needs to be defined and should be focused on the maximizing data sharing outcomes (i.e. liberalizing sustained data sharing for improved public health impact). As shared data is used, the responsibility of sharing important findings, the need for ongoing communications about analysis done with shared data, and the approval processes for publication of these findings become increasingly important to outline in the master agreement.

Political

The political processes needed to make data sharing more predictable are iterations of suggested topics in a master agreement.

Standardized Data Sharing Activity Inputs

- Purpose of sharing;
- Method for sharing;
- Authorizing entity and applicable laws (including national declaration of emergency);
- Data / Information consumers;
- Data stewards and owners;
- Change management.

The process would be triggered by the intention and value of shared data. This decision would be made by the site administrator, assuming appropriate authority to do so. As described in the use section, the purpose of sharing could be as non-specific as routine situational awareness. Continuous refinements to the NSSP BioSense Platform are enabling more granular sharing on specific data elements – however, understanding the limitations of the data (described in

standardized metadata) are necessary for proper interpretation.

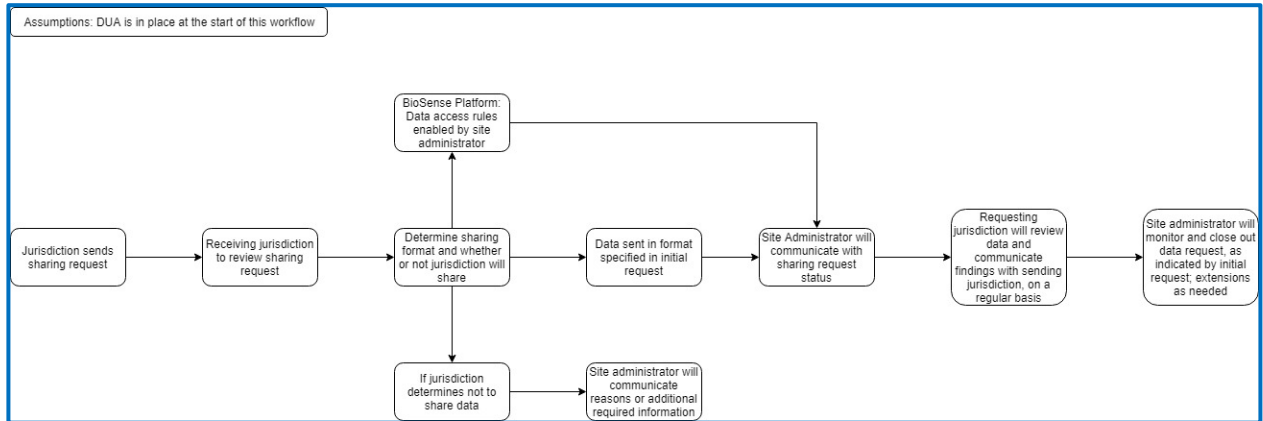
A communication plan or toolkit for information sharing could provide common language to use when interpreting and disseminating information gained from shared data. Furthermore, the toolkit should be used to communicate the value of sharing that sites have realized in improving their public health impact. As described by the communication toolkit mini-project from the NE workshop, the toolkit would include common responses to potential political barriers and talking points on the benefit of data sharing. Sharing compelling use cases could be done to gain political buy-in. The kit would also include a way to track the impact of the data sharing through documentation of success stories.

External stakeholders may need to engage with political leaders to facilitate persistent resistance to data sharing. This could be accomplished through a CSTE position statement and engagement with State Epidemiologists and State Health Officials. Continued demonstration of success and best practices through peer-driven forums (like the CSTE Annual Conference) will raise awareness and provide a growing bolus of sites participating in shared data activities. Recognizing site participation in CDC-initiated surveillance will also raise the profile of successful sites.

Understanding the landscape of syndromic surveillance data sharing is also crucial for authorizing data sharing and readily addressing emerging issues. Internal state stakeholder analysis would also be beneficial for building a case for change. Such analysis would help identify champions and stakeholders, encourage transparency, and build trust amongst parties. Furthermore, it would build awareness for, as well as the desire to tackle, the data sharing issues at hand. For national authorizations, knowing who the champions are and making the distinction between legislative processes, regulations, policies, and executive orders are critical for success.

The process of authorizing data sharing itself could be better delineated. Participants indicated a desire for a more consistent process wherein all parties understand their roles and tasks. A predictive and preventive process with methods for fast tracking and establishing continuous DUAs may involve a master data sharing agreement with use case specific addendums, reducing the need to seek permission for each emerging use case.

Figure 2. Proposed data sharing authorization process from SE mini-project



Lastly, participants highlighted to the importance of a **clear governance and accountability structure to support data sharing authorizations**. Solid data governance would make data use clear and transparent for all parties and enforce consequences for bad stewardship of shared data. Such structure would, furthermore, contribute to the stability of the authorization process and help to achieve the sharing of complete and timely data.

Capitalizing on Data Sharing Functionality

As discovered in the data sharing workshop series, the technology is available to routinely use shared syndromic surveillance data to improve public health practice. The utility can be described in multiple use cases specific to a variety of public health agency priorities. However, using shared data on the NSSP BioSense Platform for routine situational awareness and public health surveillance will prepare sites and users to respond to emerging needs in a coordinated and predictable manner.

The mini-projects identified in the workshops should be harmonized and supported through the NSSP Community of Practice. Gains were made in tangible applications of shared data for cross-border surveillance and case finding, interpretation of shared data, and how to communicate that data. The NSSP, with support from the NSSP Community of Practice, should capitalize on this work by expanding the national view. Sites should begin to opt-in to allow for data to be aggregated, at a minimum to the state level, while considering three-digit ZIP code granularity for agreed syndromes.

To react to emerging threats and considering syndromic surveillance a near real-time data source, the turn-around-time for states to participate in national queries should be shortened. This could be accomplished by ensuring that there are up-to-date contact lists for site administrators and that those site administrators have the authority to agree to participate in a national query. The inputs into that decision should be consistent and predictable as described above – who will get access to the data, how will it be used, and how will the information be publicized.

Finally, those details should be standardized in a “hub and spoke” master data use agreement. Individual sites may have different restrictions on what can be shared. Allow sites to have flexibility in their sharing parameters through the NSSP BioSense Platform, but do not restrict all sites to the most proscriptive

regulations. Site administrators will gain more agency with an agreed master data use agreement. The hub for the agreement should reside with the system owner. The NSSP should investigate how a data sharing agreement that supports sites' ability to share data in the NSSP BioSense Platform.

Conclusion

The NSSP Data Sharing Workshop Series National Capstone event reinforced the value proposition for sharing syndromic surveillance data across jurisdictional lines. The utility of shared syndromic surveillance data is as varied as site-specific surveillance use cases including infectious diseases, injury prevention, environmental health, and general situational awareness. The value of sharing data, as demonstrated by multiple sites, needs to be highlighted to key stakeholders to accelerate political buy-in and decision making by state and local leadership. Not all states may need a DUA – however, a master agreement that allows sites to share within their legal confines and governs the stewardship of shared data will allow more states to share data.

Key stakeholders can help drive adoption. Data sharing success stories should be promoted in appropriate forums (like CSTE Annual Conferences) with a strong position by national associations of state and territorial public health leaders. Successful surveillance initiated by the CDC should also visibly recognize the sites that contribute data to those projects. The CDC should continue to encourage national level reporting using the NSSP BioSense Platform through grant mechanisms (as was done for the opioid overdose reporting).

The projects charted during the workshop series should be consolidated and continued through the NSSP Community of Practice to produce the illustrative outputs described in their charters. Besides the shared dashboards, analytics, and metadata required for improved interpretation, the workshops all benefited from using common syndrome definitions with extensive documentation on how they were defined. This process should continue for all new common syndrome definitions.

The NSSP and the NSSP Community of Practice would increase utility of the system for shared data by increasing the granularity of the “national view” on the NSSP BioSense Platform. Currently, the national view is restricted to HHS regions, providing limited value to federal, state, or local users. By increasing the geographic granularity of the national view to state or three-digit ZIP code, the community would push the boundaries on real-time national surveillance and provide greater utility without necessarily requiring changes to current laws or practice.