CSTE

COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS

NSSP REGIONAL DATA SHARING WORKSHOP SERIES

Final Report

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with support from: KAHUINA CONSULTING

Contents

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Additionally, the workshops benefited from significant subject matter expertise from the CDC's NSSP analysts and managers that allowed for rapid technical assistance in using the tools on the NSSP BioSense Platform.

CSTE provided valuable logistics, administration, and participant engagement throughout the workshop series.

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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), hosted four regional data sharing workshops to improve the sustained use of shared data on the BioSense Platform managed by the National Syndromic Surveillance Program (NSSP). The purpose of the data sharing workshop series was to strengthen public health agency capacity for syndromic surveillance (SyS) and enhance situational awareness using real-time electronic health data from emergency department (ED) settings through interjurisdictional data sharing and surveillance practice collaborations.

The workshops were designed and facilitated by Kahuina Consulting, LLC to guide participating jurisdictions on a structured path of realizing the value of data sharing, appreciating that value, and utilizing the value through continued regional projects that rely on access to and utilization of shared data in the NSSP BioSense Platform.

Workshop objectives included:

1. *To enhance syndromic surveillance skills to better support agency activities for opioid crisis response*
2. *To examine and share best practices in SyS analytic methods and NSSP tool use*
3. *To develop action steps for establishing or strengthening interjurisdictional data sharing*
4. *To foster collaborations among the peer network of SyS professionals*

The workshops convened 135 participants from 44 states (including 14 local public health agencies) with a range of public health and SyS experience and skill. The average participant was a mid-career SyS analyst / epidemiologist. The process was participant-driven with tangible exercises designed around evaluating and using a standard syndrome definition on shared data with a common tool: NSSP BioSense Platform's ESSENCE tool (BioSense ESSENCE).

The workshops succeeded in enhancing SyS skills to better support the Opioid Crisis response through improved skill gain across all evaluated categories. There was a noticeable shift in self-assessed competence with the majority of participants agreeing that they could perform tasks without assistance after the workshops. Colleagues were able to learn new methods for analyzing and interpreting data on BioSense ESSENCE from each other and CDC technical experts. Seventeen mini-projects were chartered with defined action steps to strengthen and continue inter-jurisdictional data sharing. Furthermore, a peer network of SyS analysts was fostered, enhancing trust and further collaboration amongst regional and national working groups.

Unlike the previous workshop series (2013-2016)[1], technology is no longer a barrier to sustained data sharing. NSSP's BioSense Platform can successfully enable site-to-site data sharing and analysis with trusted tools and syndrome definitions. Planned refinements to data sharing rules will simplify this process.

[1] Syndromic Surveillance Data Sharing in the U.S.: The value proposition, principal barriers, and collective solutions identified by state and local public health practitioners from 2013 -2016. Reported to the Association of State and Territorial Health Officials; October 2016.

Recommendation and next steps include:

- Improving data interpretation through enhanced metadata and data quality reports accessible on the BioSense Environment.
- Shared syndrome-specific dashboards and visualizations (managed and unmanaged) can democratize expertise and help close skill gaps.
- Provide additional standardized training courses focused on a progressive skill gain to improve SyS skills and knowledge of the BioSense Platform as it evolves.
- Identify, communicate, and promote political and legal solutions to agency decision-makers; a common data use agreement (DUA) with a standard and predictable process for specific use cases may facilitate broader data sharing for state and local sites that remain hampered by restrictive regulations.
- Harmonize and support the mini-projects chartered during the data sharing workshop series.
- Continue support of the Community of Practice and streamline communication and activities across multiple initiatives, including the following mini-project categories:

    - Utility of data through shared dashboards;
    - Interpretation of shared data through understanding metadata and quality;
    - Improved communication amongst the practice community and intra-agency leadership;
    - A formal approval / DUA and process to agree to share data.

Background

CDC's National Syndromic Surveillance Program (NSSP) continues to promote syndromic surveillance (SyS) practice at the state and local levels by encouraging public health agencies to participate in the BioSense Platform. This has led to newly onboarded sites, administrators, and users with diverse skill sets and familiarity with SyS practice, growing the community of local, state, and national users. CSTE, in collaboration with CDC, convened four data sharing workshops to compound on previous work to improve sharing of SyS data through the NSSP BioSense Platform. The workshops were geographically divided (South + East [SE], Northeast [NE], West [W], and Midwest [MW]) to bring neighboring jurisdictions and regions together. The goals of the workshops were 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.

NSSP Syndromic Surveillance Data Sharing Workshops 2019

South + East (SE): April 30 – May 1

Northeast (NE): June 11 – 12

West (W): July 23 –24

Midwest (MW): August 6 – 7

Advances in the functionality of the shared tools on the NSSP BioSense Platform have improved the site administrator ability to share data more specifically with other users on the system. The technical functionality of the Access Management Center (AMC) site administrator tool on the Platform is further enforced through a code of conduct that all end-users are required to read and acknowledge prior to engaging with the system. These changes address previously identified challenges to routine data sharing and set a new baseline for the workshops.

The activities for all four workshops were centered on Enhanced State Opioid Overdose Surveillance (ESOOS) priorities[2], specifically to increase the timeliness of surveillance of non-fatal overdose-related events. Continued national efforts to prevent and respond to the ongoing Opioid Epidemic have benefited from frequent state data submission by to CDC. For this reason, additional funding has been provided to states to combat opioid-related injuries through increased surveillance under the ESOOS grants. Information provided by state and local SyS systems has proven to be a critical component of the national response. Thus, the Opioid Epidemic acted as the use case explored in the workshops.

Kahuina utilized five syndrome definitions (i.e., All Drug, Heroin, Opioid, Stimulant, and Suicide) developed by the CDC with syndromic surveillance community input throughout the workshop series. The design of the workshops allowed participants to rapidly evaluate these syndrome definitions and apply those definitions to their regional shared data in the BioSense environment. Mini-projects that utilized these syndrome definitions were chartered to foster continued exploration of the utility of shared data on overdose surveillance, which included baselining for situational awareness, reporting, and initiating a public health response.

Kahuina Consulting, LLC, in consultation with CSTE, CDC, and the workshop participants, designed and delivered the workshop series. Kahuina's facilitation methodology is based on a model that utilizes a

[2]Centers for Disease Control and Prevention, NCIPC. (2019, Jul 16). Enhanced state opioid overdose surveillance. https://www.cdc.gov/drugoverdose/foa/state-opioid-mm.html

non-formal education (NFE) approach,[3] which features self-directed learning and peer-to-peer problem solving. The approach actively engages participants in identifying their learning needs and methods with guidance from a facilitator.

Each workshop had the same objectives, which have been outlined below:

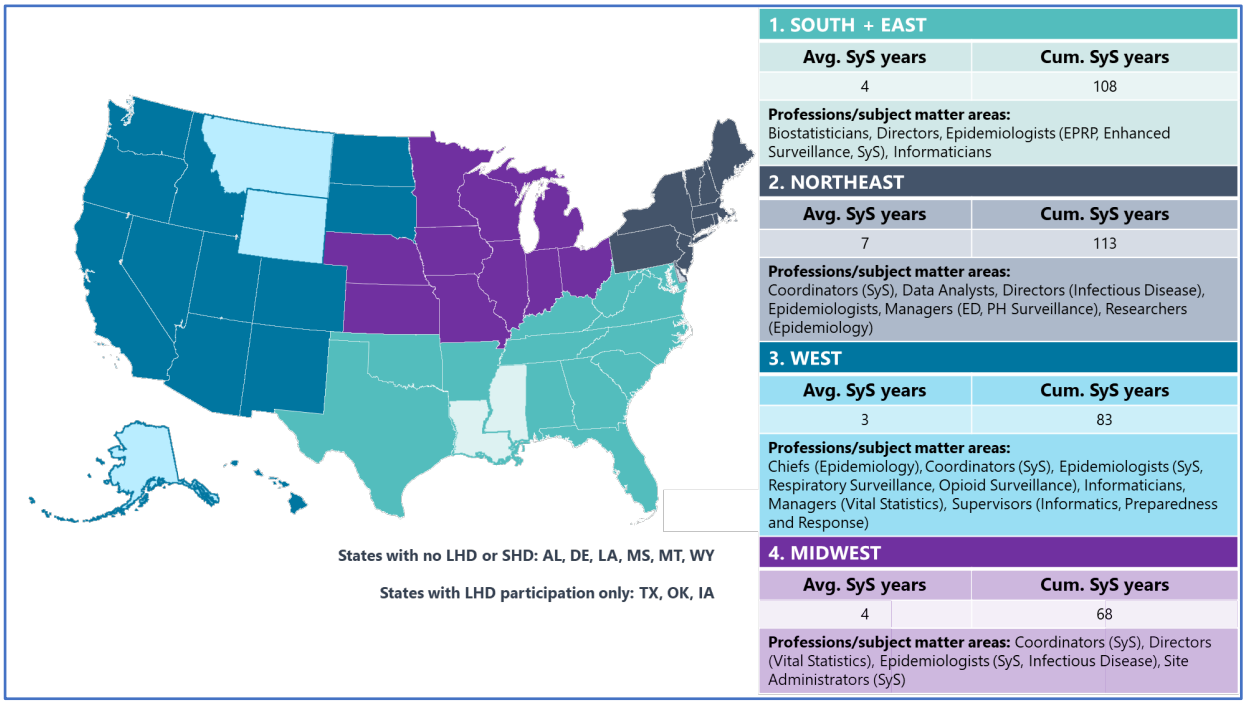
1. Enhanced SyS skills to better support the Opioid Crisis response
2. Examined and shared SyS analytic methods and NSSP BioSense Platform tool usages
3. Developed action steps for establishing or strengthening inter-jurisdictional data sharing (i.e., inter-state and state to federal)
4. Fostered collaborations among the surveillance professional peer network

Workshop Description

The regional workshops convened 135 state and local public health agency representatives from every HHS Region. Participants' experience ranged from novice to highly experienced SyS analysts as well as users of the ESSENCE SyS system. Their agency roles were predominantly SyS analysts/epidemiologists. Additional participant job titles included opioid-specific epidemiologists, program managers, department heads (informatics and epidemiology), privacy officer, and data managers. These staff were, on average, mid-career professionals with significant experience at their health agency – however, this ranged from entry-level to 30 years of experience. Each workshop cohort represented a very diverse group of skill sets and experience, but all had limited representation from decision-making authorities or agencies.

[3] Nonformal Education Manual, U.S. Peace Corps, Information Collection and Exchange, Publication Number M0042, Reprinted 2011.

Figure 1: NSSP Workshop Participation



As described in Figure 2 below, the workshops were designed and tailored to each region with user input collected through pre-assessments and virtual design calls. The in-person meetings provided structured activities designed to inform SyS methodology for the opioid response and improve inter-jurisdictional data sharing. Post-workshop follow-up activities (post-assessment and virtual meeting) evaluated participant and community progress towards the defined outcomes.

Figure 2: Workshop Logic Model

Inputs	Activities	Outputs (products)	Outcomes
Virtual Pre-Meetings ➢ Participant expertise and interests ➢ One or more SyS epidemiological practices to improve; e.g., opioid overdose or injury surveillance ➢ Preparation work; i.e., set-up workshop data sharing, review references, provide system information ➢ Jurisdictional SyS data assessment	**Day 1: In-person** ➢ Use and share real SyS ED visit data to collaboratively investigate and improve a mutually important SyS practice(s) on the BioSense Platform ➢ Appreciate the actual value of sharing data for public health	➢ Evaluated four opioid crisis related classifiers ➢ Developed and shared surveillance products in ESSENCE ➢ Listing of possible ways to utilize the surveillance products for public health actions ➢ Articulation of SyS data sharing value ➢ Products to create with more sharing	➢ Increase SyS analytic skills ➢ Increase skill with NSSP tools
	Day 2: In-person ➢ Identify what will make collaborators more able to share data and benefit ➢ Form mini-projects that either advance surveillance practice with shared data, or advance ability to share data and collaborate ➢ Work on projects together, in-person, and prepare for virtual collaborations	➢ Prioritized listing of items that will enable more or improve sharing and collaborations ➢ At least four mini-project charters ➢ Project work and next steps	➢ Enhance public health surveillance practice ➢ Enhanced collaboration among the peer network of regional surveillance professionals ➢ Appreciate the value of SyS data sharing

Design Calls

Prior to hosting any workshop design calls, an assessment was delivered to gauge current self-identified experiences with SyS methodologies, system functionality, and current data sharing with CDC programs and other jurisdictions. Additionally, a pre-workshop assessment asked participants to share their expectations for the workshop and what areas they wanted to explore related to shared data and its intersection with the Opioid Epidemic.

Across the four workshops, participant goals included:

- Strengthened relationships with colleagues;
- Understanding of best practices and developing actionable plans for data sharing;
- Improved technical competency on shared tools and data quality analysis; and
- Understanding solutions to governance and legal challenges for data sharing.

In order to develop activities and eventual mini-data sharing projects focused on enhancing timely use of surveillance data to support CDC's and states' Overdose Prevention in States (OPIS) efforts[4], participants were asked to identify which aspects of SyS they were interested in exploring with their colleagues. The common groupings of interest focused on syndrome definition evaluation, analysis, alerting, and application/utility of the surveillance.

Each participating BioSense site was asked to share data on the BioSense Platform with other sites attending the regional workshop. The NSSP technical team created user groups for each workshop with which sites could share their data. However, a lack of familiarity with how to establish specific rules in the BioSense AMC required additional just-in-time training from NSSP representatives to ensure the developed rules would allow access to the shared data. The data granularity (i.e., aggregate or full data details) and analysis grouping (i.e., patient location and/or facility location) were set by each site.

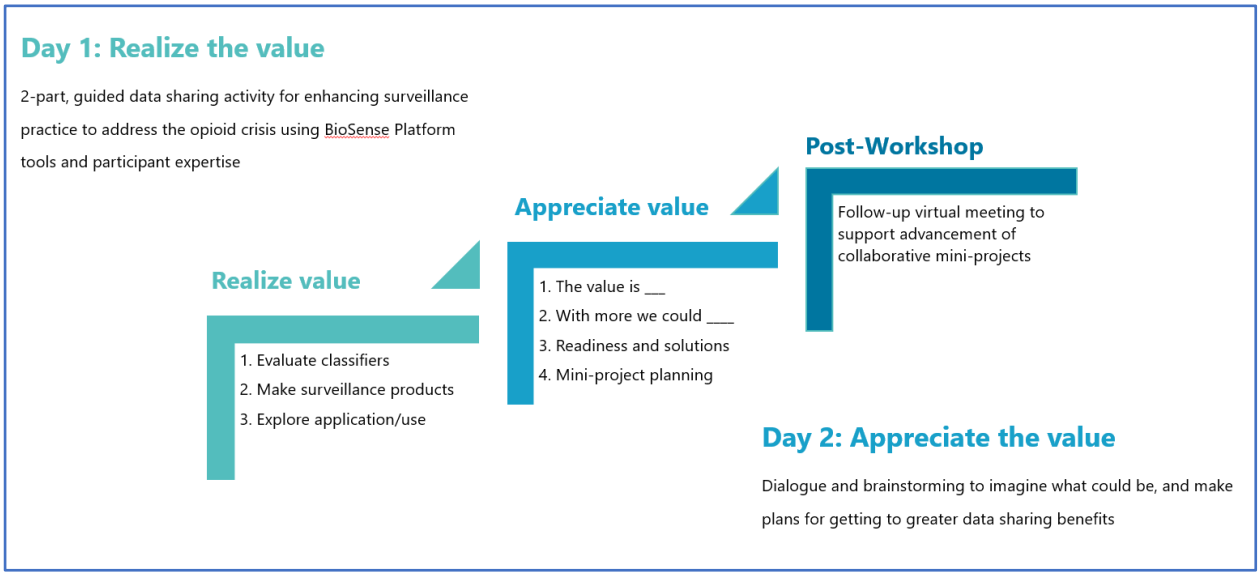
Most sites were able to share at least aggregate data prior to the workshop with other workshop participants.

In-person Workshops

The in-person workshops were delivered over two days, with Day 1 focused on realizing the value of shared data, and Day 2 focused on appreciating the value of shared data to launch participants into sustained projects that leverage shared data.

[4] Centers for Disease Control and Prevention, Opioid Prevention, State Information (Sept 3, 2019). https://www.cdc.gov/drugoverdose/states/index.html

Figure 3: Workshop activity goals



Data Sharing Activities

The Day 1 data sharing activities were designed to explore the syndrome definitions developed for drug-related injury surveillance and the functionality of the BioSense ESSENCE application. Participants were divided into small teams with a mix of novice and experienced SyS users. The day was structured around two activities that encouraged teamwork using shared data and the NSSP BioSense Platform suite of tools, specifically the BioSense instance of ESSENCE (referenced as BioSense ESSENCE in this report). The teams were required to organize around one BioSense ESSENCE operator that navigated the system.

Data Sharing Insights

1. MAJORITY OF SITES SHARED DATA USING BIOSENSE PLATFORM;
2. COMPREHENSIVE DOCUMENTATION FACILITATES USE OF SHARED SYNCROMES;
3. PEER-TO-PEER LEARNING AND SKILLS TRANSFER FACILITATED BY IN-PERSON ACTIVITIES;
4. SITE SPECIFIC META-DATA REQUIRED FOR SHARED DATA INTERPRETATION.

Activity 1

Each group was assigned a syndrome definition to evaluate using the Chief Complaint Query Validation (CCQV) data set available in BioSense ESSENCE. Participants answered evaluative questions based on community-defined guidance. This shared data set was chosen for the syndrome definition evaluation to highlight its availability and the opportunity it provides to refine a syndrome with the majority of captured chief complaints in BioSense ESSENCE but without any other defining variables (e.g. age, facility, etc.). Many users were unfamiliar with this feature/its utility.

The chosen syndrome definition (or classifiers) explored were CDC-developed, including All Drug Overdose, Heroin, Opioid, Stimulant, and Suicide classifiers. The groups evaluated the information being queried through the CCQV data set and applied the syndrome definitions to the shared data set. These classifiers all had well-documented definitions that explained what terms and discharge diagnosis were

included and excluded from the query. This documentation allowed teams to rapidly assess general definition validity with no recommended changes.

This highlights the value and ongoing need to continue providing proper documentation for such shared (or CDC-developed) syndrome definitions.

Activity 2

The second data sharing activity focused on developing surveillance "products" (i.e., trendlines, maps, dashboards, and alerts) based on the evaluated syndrome definitions. Groups were instructed to use the shared data set to explore the epidemiology of their surveillance results. Besides the general products developed, participants also learned how to share developed products with other BioSense ESSENCE users.

This activity allowed for on-the-job training and skill transfer between the experienced and novice ESSENCE users, and also highlighted the need for continued training and communication of new features on BioSense ESSENCE.

Working with colleagues across jurisdictional borders fostered needed connections and built trust for sustained cooperation. Additionally, participants benefited from CDC super users demonstrating use of BioSense ESSENCE and the AMC interface to answer several functionality questions. **The interpretation of shared data still needs to be explored**; there may be specific caveats and more generalizations that need to be made when analyzing shared data compared to one's own site data. This need was emphasized by state and local analyst and reflected in the mini-projects further described below.

Affinity Grouping

Day 2 of the workshop focused on appreciating the value of data sharing through affinity mapping with the entire group. The approach and questions differed slightly between the first two workshops (SE and NE) and the second two workshops (W and MW) based on lessons learned and participant input during workshop-specific design calls. The general idea was to identify the value of data sharing by eliciting the utility of Day 1 activities. Participants were asked to reflect on the following statement and then group responses into like categories:

"_____ was delightful or super useful when you shared data and collaborated with me yesterday."

Responses to this statement were similar across the four workshops, with participants generally appreciating both opportunities to work with and learn from their colleagues and to uncover new functionalities of the BioSense ESSENCE tool. The jurisdictions that do not currently participate in BioSense expressed a deeper understanding of the platform and the supporting community following Day 1 activities. Several non-participating jurisdictions emphasized using this experience to galvanize support from leadership to actively participate in BioSense.

Following this exercise, participants were asked to aspire to the next level of SyS and public health practice by reflecting on the following statement:

"With more sharing and collaboration, we could _____."

The resulting categories were focused on improving the efficiency of public health surveillance and response. Specific projects that could benefit from shared data were identified, including cross-border

surveillance and regional situational awareness and response. Themes emerged across the four workshops addressing efficiencies in day-to-day surveillance activities, such as sharing syndrome-specific dashboards with other users for emerging surveillance needs.

Each workshop was asked to identify what is needed to get them ready to actively share data, assuming the following:

1. Data will be shared through the BioSense Platform for a specific purpose;
2. There is a desire to share data;
3. Sharing is specific to CDC Programs and other BioSense sites.

The second half of workshops (W and MW) were given an opportunity to reflect on their submitted pre-workshop assessment of sharing readiness and provided with a barrier to data sharing taxonomy[5] to review prior to completing this statement:

"_____ will get us ready and sharing."

Two major categories emerged from Question 3 : leadership and legal. Both categories relate to some form of permission that site administrators look for before sharing.

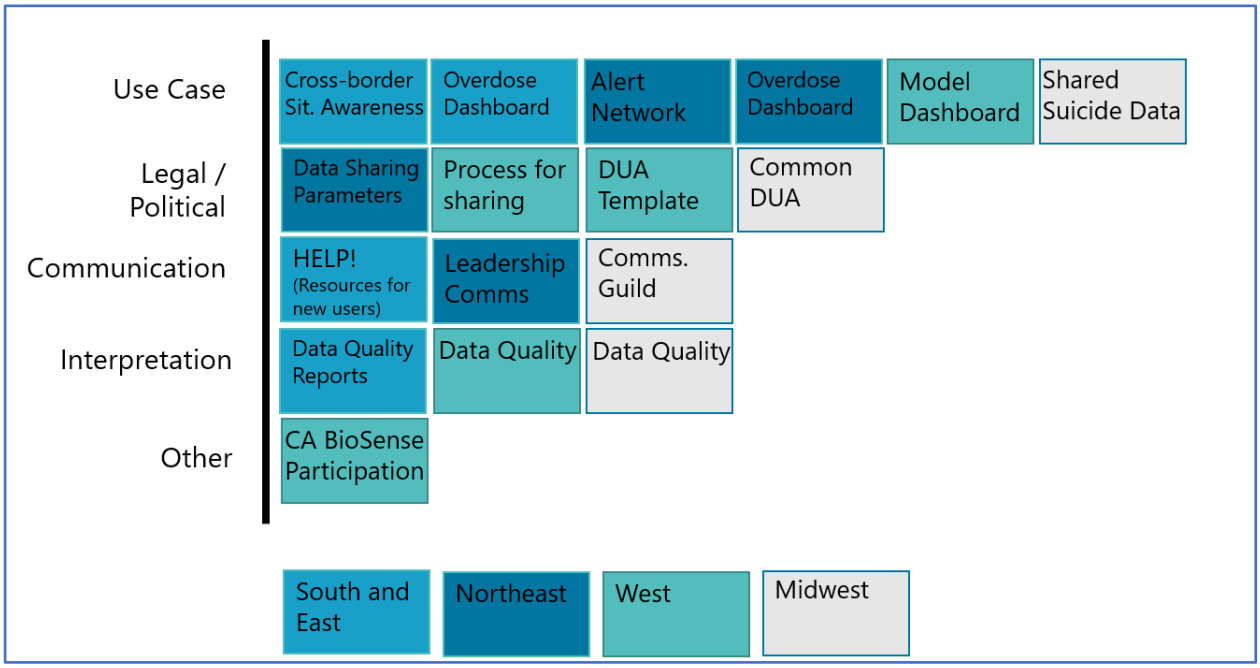
Participants voted on the groupings from the second question (primarily technical) and the groupings from the third question (political) to charter mini-projects. The mini-projects were focused on initiating and sustaining data sharing on the BioSense Platform.

Project Initiation

Figure 3 illustrates the commonalities of mini-projects chartered across the four workshops. The majority of projects were focused on developing surveillance products for a particular use case. Others addressed the need for a tangible reason or public health interest to share data, which was cited in every workshop as a pre-requisite to share data. Additional project interests ranged from cross-border situational awareness to very-specific suicide morbidity trends included in regional reports.

[5] *van Panhuis WG, Paul P, Emerson C, et al., A systematic review of barriers to data sharing in public health. BMC Public Health. 2014;14(1):1-9.*

Figure 4: Mini-projects by category and workshop



Only one participant out of the 135 workshop attendees represented an agency's legal office as a privacy officer for the state health department. However, three out of the four workshops highlighted a need for some form of data use agreement to feel comfortable sharing data through the BioSense Platform (projects chartered under the legal/political category in Figure 4). **These project teams could harmonize to articulate the need and requirements for a shared DUA and what entity holds the master copy.**

Assuming a DUA is in place, the authorizing process for both sharing and sharing requests needs to be fully mapped out and adhered to. The rapidity of granting access to shared data should match the recency of the data and speed at which public health threats evolve.

Several projects were chartered to assist new users in engaging with the technology and NSSP Community of Practice, advocating the utility and value of data sharing with leadership, and improving knowledge management. The workshops were held shortly after the sunsetting of the International Society for Disease Surveillance (ISDS), the previous home of the SyS community of practice, and this may have influenced the desire to have more consistent communication.

Most workshops also initiated projects focused on interpretation of shared data through a better understanding of data quality. Specifically, the metadata and representativeness of shared data feeds is important when interpreting data from other sites with limited context.

Skills Change

A pre- and post-workshop assessment was delivered to all participants to gauge the workshop effects on improving knowledge and experience with SyS methodologies, system functionality, and data sharing.

The responses from the pre- and post-workshop assessments were compared across the four regional workshops to determine skill changes resulting from the workshops. The SyS skills assessed were categorized into the following areas:

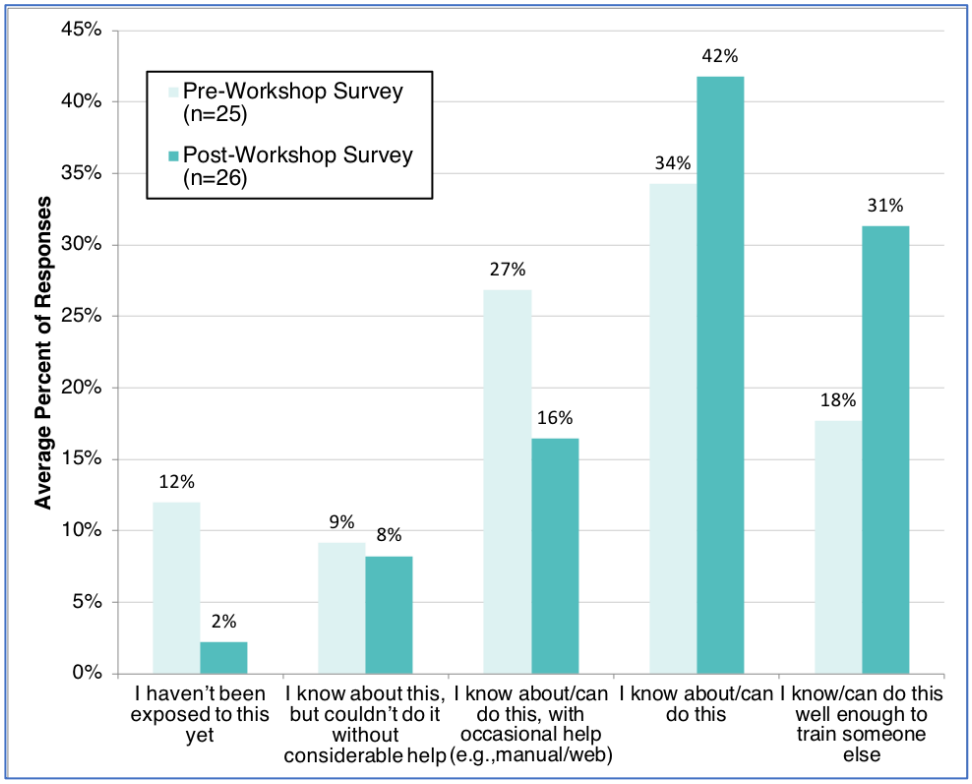
1. Sorting and Grouping of Emergency Department (ED) Data - SAG
2. Data Analysis and Interpretation - DAI
3. Communicating Syndromic Surveillance (SyS) Information - COMM
4. Data Quality Assurance - DQA
5. Data Sharing - DS
6. Emerging Technologies - ET

An 'improvement in confidence' for a SyS skill was defined as an increase in participants indicating that they knew/could do a task or skill with or without help. 'Greatest improvements in confidence' meant participants eventually knew/could do a task or skill without help, including being able to do it well enough to train someone else.

South + East

Participants from the South + East Workshop indicated improvements in confidence across all six categories of SyS skills following the in-person workshop. The areas with greatest increase in confidence included Sorting and Grouping ED Data, Data Analysis and Interpretation, Communicating SyS Information (Graph 1), and Data Sharing. For these areas, there was at least a 20% increase in proportion of respondents saying that they knew/could do a task or skill without help. In the remaining categories (i.e., Data Quality Assurance and Emerging Technologies), there was only a 4% increase in proportion of respondents indicating they could do the task or skill without help. Of the six categories, Emerging Technologies was the only skill area that did not show an increase in proportion of practitioners who could do a task well enough to train someone else.

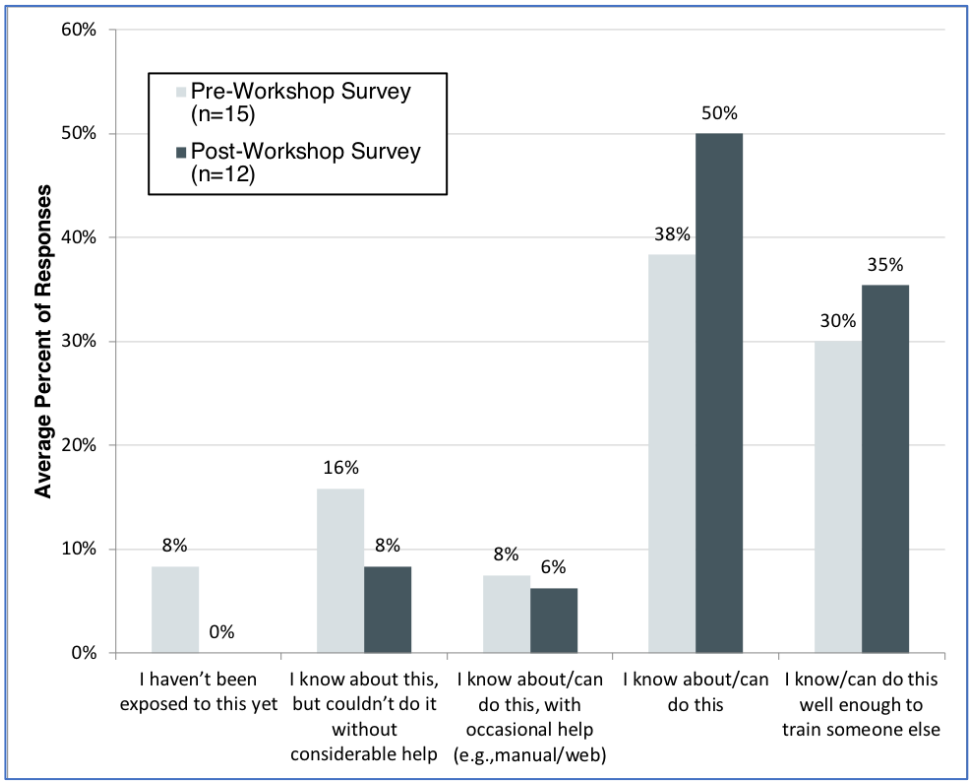
Graph 1: South + East Workshop – Communicating Syndromic Surveillance Information Skills Change



Northeast

For Northeast Workshop participants, the categories of skills for which there were the greatest improvements in confidence post-workshop included Sorting and Grouping ED data (Graph 2), Data Analysis and Interpretation, and Communicating SyS Information. The category of Data Analysis and Interpretation showed the highest increase (14%) in proportion of individuals saying they could do a task and well enough to teach someone else. Respondents still indicated improvements in confidence for Data Quality Assurance and Data Sharing skills – though, a lower proportion of individuals stated they could do a task or skill without help (<12%) in those categories compared to the other three categories (>16%). The one area for which there was no change in proportion of participants being able to do a task or skill without help was Emerging Technologies.

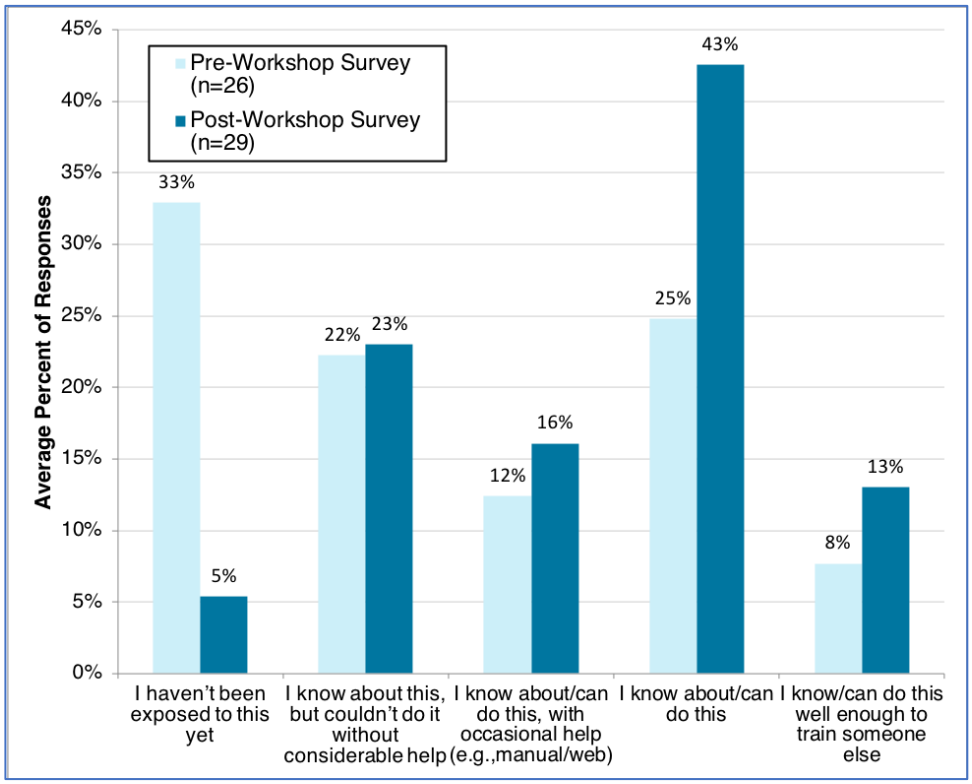
Graph 2: Northeast Workshop – Sorting and Grouping Emergency Department Data Skills Change



West

Participants from the West Workshop also indicated improvements across all categories of SyS skills following the workshop. Respondents noted the greatest increase in confidence of skills in Communicating SyS Information (20% increase) and Data Sharing (23% increase) (Graph 3). There was also at least a 10% increase in the proportion of participants saying they could do a task or skill without help in the areas of Sorting and Grouping ED data, Data Analysis and Interpretation, and Data Quality Assurance. Interestingly, the greatest increase in the proportion of participants who stated they could do a task or skill well enough to train someone else was for Sorting and Grouping ED Data skills (17%).

Graph 3: West Workshop – Data Sharing Skills Change



Midwest

The area of greatest increase in confidence for Midwest Workshop participants was in Data Sharing following the in-person workshop. There was an overall increase in the proportion of individuals indicating they could do a task without help for the categories of Sorting and Grouping ED Data, Data Analysis and Interpretation, and Communicating SyS Information. However, there was also a *decrease* in proportion of respondents indicating they could do a task or skill without help. Across all six categories of skills, there was a decrease in proportion of individuals indicating they could do a task well enough to train someone else. This is most likely a reflection of the response rate and the people that responded, described below.

Fewer experienced participants completed the post-workshop assessment compared to the pre-workshop assessment. The average years of SyS experience for respondents who filled out the pre-workshop assessment was 4.1 years, while the average years of experience for those who filled out the post-workshop assessment was 2.1 years. In contrast, the average of years of experience for respondents differed less than 1 year for the other three regional workshops (Table 1). Missing responses by more experienced practitioners for the Midwest post-workshop assessment skewed the results toward the middle of the curve.

Graph 4: Midwest Workshop – Data Quality Assurance Skills Change

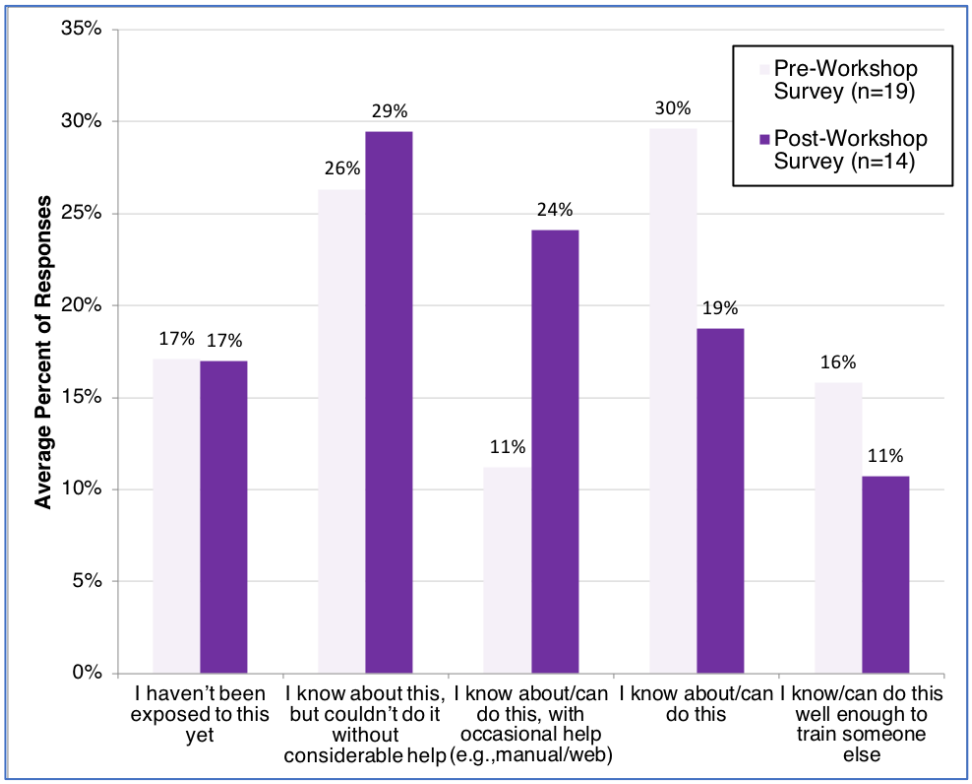


Table 1: Comparison of Average Years of Syndromic Surveillance Experience of Respondents Across Workshops

Respondent Average Years of SyS Experience			
Workshop	**Pre-Workshop (yrs)**	**Post-Workshop (yrs)**	**Difference (yrs)**
South + East	4.12	4.06	0.06
Northeast	7.47	6.67	0.8
West	2.67	2.84	-0.17
Midwest	4.05	2.14	1.91

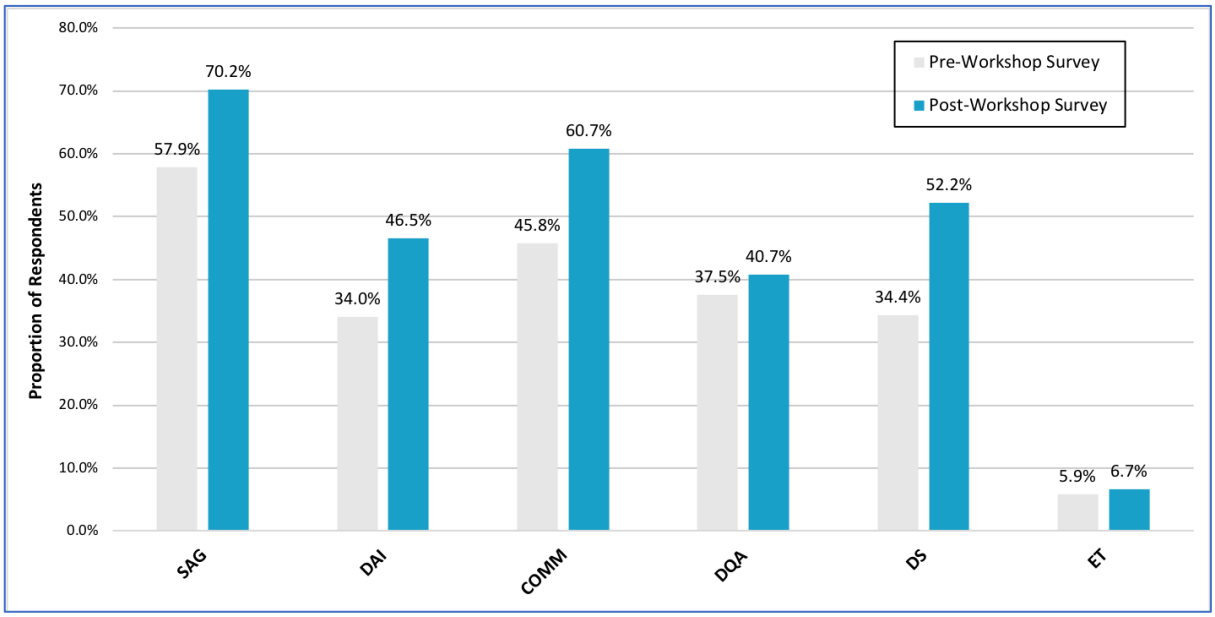
Across Regions

Participants from each regional workshop gained exposure and competency across the six different categories of SyS skills assessed as a result of workshop participation (Figure 5). Competency was defined as knowing and being able to do a task or skill without help, including being able to do it well enough to train someone else. The categories for which participants from all four regional workshops indicated greatest improvements of confidence were Data Sharing and Communicating SyS Information. The category for which participants noted the least change in confidence, particularly with practitioners indicating that they would be able to do a skill without considerable or occasional help, was Emerging Technologies (which was not directly addressed during the workshops). Overall, every category showed improvement in confidence of skill across jurisdictions such that individuals could do a task or skill with or without help. The exception is in the category of Data Quality Assurance for the Midwest workshop participants, as there was no net change in the proportion of individuals being able to do a skill with or without help pre- and post-workshop. This anomaly may be attributed to reasons previously discussed.

Importance of In-Person Meetings

WORKSHOP PARTICIPATION INCREASED COMPETENCY ACROSS KEY SYNDROMIC SURVEILLANCE SKILL PRIORITIES.

Graph 5: Summary of Competency Gained in Syndromic Surveillance Skills by Total Proportion of Responses Across Regional Workshops



Public Health Practice Gains

The workshop series provided the opportunity to evaluate five syndrome definitions in a real-world setting with local and state syndromic surveillance epidemiologists. These syndromes were created by CDC with input from the NSSP Community of Practice, and while well-documented, they had not been "field tested" until the workshop. The latest versions of the syndrome definitions (All Drug Overdose,

Opioid Overdose, Heroin Overdose, Stimulant Overdose, and Suicide) coded in ESSENCE as chief complaint and discharge diagnosis syndromes were those evaluated at the workshops. No significant changes to the syndrome definitions were suggested at any workshop – however, clear documentation and standardized methodology for evaluation was key to syndrome validation, with a bias towards more sensitive (rather than specific) queries.

Because these syndrome definitions rely on both chief complaint and discharge diagnosis, the completeness of each of these fields in site data feeds is essential to the interpretation of the results. Knowing and understanding these differences in representation, completeness, and timeliness is critical to interpreting shared data. The need for this understanding manifested in both new ways to look at data quality through available ESSENCE tool features and the establishment of mini-projects to further document the metadata elements needed by site.

Practical Gains

1. REAL-WORLD EVALUATION OF SHARED SYNDROME DEFINITIONS;
2. NEW FUNCTIONALITY OF BIOSENSE ESSENCE EXPLORED;
3. AMC SHARING RULES ESTABLISHED FOR REGIONAL GROUPS;
4. IMPROVED COMMUNICATION BETWEEN REGIONAL PROFESSIONALS.

The mix of experience in teams led to new dashboards, both for surveillance and data quality. Both managed and unmanaged dashboards were shared within teams. Managed dashboards provide an opportunity for advanced regional users or CDC super users to develop and maintain a specific dashboard that can be shared with less experienced or resourced sites. By distributing the burden of developing surveillance products akin to “Mutual Aid,” sites with limited SyS resources can focus on interpretation.

The workshop experiences allowed site administrators and analysts to reflect on the granularity and type of data shared for particular use cases. The level of customization in the AMC tool is expected to change, allowing more specific sharing. Not all use cases require full patient details; aggregate counts for a query result may be sufficient for regional trends. Full data details are better suited for cross-border case finding of a site’s residents and were often cited by local health agency representatives with a mandate to conduct individual case investigations.

Facility location and patient location are two distinct ways to classify patient visits in ESSENCE. The visit classification needs to be considered in any data sharing use case. For instance, the residence of the patient may be needed for cross-border surveillance whereas the visit facility may provide better information for regional trends.

The chartered mini-projects have also produced regional projects to define rules in the AMC to allow visibility of a site’s residents in bordering states (e.g. North Carolina, Tennessee, and Virginia cross-border project) through BioSense ESSENCE. Other projects have identified existing regional data-sharing activities to enhance with SyS data using a shared definition (e.g. Region 5 Suicide Report).

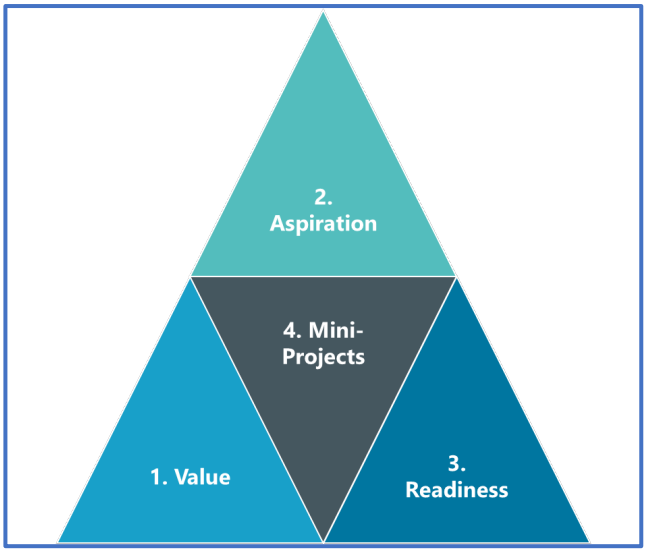
Most importantly, the workshops identified a need for better communication within the BioSense user groups and community of practice. SyS epidemiologists and analysts (especially grant-specific cadre) are routinely changing, and the SyS workforce is growing. Personal networks of users across the

country can no longer provide adequate coverage during an event. NSSP and collaborative partners should consider solutions for users looking for contacts to initiate surveillance projects before, during, and after an event of public health importance.

Appreciative Inquiry Output

The workshop activities were designed around an appreciative inquiry framework to 1) discover the value of data sharing through shared activities, 2) dream and aspire for what could be done with more data, and 3) design and deliver the paths forward to realizing the dream: improved public health practice with better access to and utility of shared data. This approach was embedded in the workshop design, and summary insights for each component are included below in reference to Figure 5.

Figure 5. Building blocks of appreciative inquiry



1. Discovery: Value of sharing data

Trust and earnest collegiality among jurisdictional peers facilitate the exchange of ideas, experiences, and contextual knowledge that makes SyS data sharing possible, meaningful, and useful. Collaborating using common tools like those included in the BioSense Platform standardizes the approach and raises professional skills.

2. Dream: Aspiration with more value

In a world where data are shared and the value is present, the public benefits when public health professionals are better equipped to identify disease trends and pre-emptively act across borders to improve outcomes and secure population health.

3. Design and Deliver: Getting to readiness

There is a strong willingness and readiness to sustain data sharing – yet, analysts and program managers lack the agency to approve or seek approval to share data. A defined surveillance scope with a clear process to authorize sharing will facilitate continued data sharing. A clear understanding of legal solutions from agency leadership is needed for program managers to identify and advocate for projects that will benefit from shared data.

4. Design and Deliver: Mini-projects

There were four consistent themes throughout the workshop mini-projects (Figure 4) developed to utilize existing shared data and advance sustained sharing:

- **Utility of data through shared dashboards;**
- **Interpretation of shared data through understanding metadata and quality;**
- **Improved communication amongst the practice community and intra-agency leadership;**

- **A formal approval / DUA and process to agree to share data.**

These projects remain regionalized; effort should be taken to combine like projects where appropriate and consider expanding the "national view" from HHS regions to state-level trends for selected syndromes.

Conclusion

The NSSP Data Sharing Regional Workshops provided a valuable opportunity for a diverse mix of syndromic surveillance analysts to convene, actively share data through the BioSense Platform, and manipulate shared analysis using the BioSense ESSENCE environment. **The participants agreed that meeting colleagues and working with them on concrete activities established a level of trust and comfort that could not be replicated in a virtual environment.** The addition of technical experts(both at the state and local level as well as CDC) was a tremendous benefit to quickly progress past skill gaps and build trust between site users and NSSP SMEs. These relationships are essential to progressing the work initiated in the mini-projects.

BioSense sites are in varying stages of readiness to share data with other sites and CDC programs. However, the value of shared data is clear and compelling. The workshops were framed to encourage sites to share data for the in-person activities. With few exceptions, motivation from the analyst/epidemiologist perspective is not a barrier. NSSP should continue to highlight examples of successful data sharing and the public health impact in those sites – such impact should be measured in both improvements in health outcomes (e.g., improved timeliness of signal identification, decreased burden of disease due to early detection, etc.) as well as efficiency gains in work processes (e.g., reporting requirements for ESSOS grants). **CSTE can elevate the conversation of value to their membership, especially leadership and State Epidemiologists, to standardize the practice of routine data sharing.**

Technology no longer presents a significant barrier to data sharing. Active sharing was accomplished in the BioSense environment at each workshop. This allowed for standard syndrome definitions to be applied to the regional-specific shared data set, and the approach taken to rapidly "validate" the syndrome definitions was essential to sites and/or analysts trusting the definition. No significant changes were made to any of the syndromes after reviewing the comprehensive documentation, discussing the intent of the syndrome, and considering the results. This approach should be replicated when utilizing established syndrome definition and/or considering new CCDD syndromes for emerging public health threats.

BioSense ESSENCE skill is improving. Yet, the rapid expansion and turnover of SyS analysts coupled with an evolving system creates skills gaps. These workshops did not require a working knowledge of ESSENCE, but were they were also not designed to impart technical skill in using the NSSP suite of tools. Skills were gained, but **dedicated training courses should be matched with a gradual progression in skill from beginner basics to advanced integration with other programs through the NSSP ESSENCE API.**

Interpreting SyS outputs requires an understanding of the underlying data – the completeness, accuracy, representativeness, and timeliness of submitted data affects the interpretation. **Continued work to define metadata standards and make that information accessible to users will improve shared data utilization.**

Many jurisdictions still cite a need for a formal legal process to enable data sharing with other BioSense sites. Defining the legal framework and process for sharing data still needs to be completed. The most efficient model is a hub-and-spoke DUA where participating agencies all sign the same DUA. Additionally, participants suggested that sharing needed to be grounded in a particular use case. These use cases may form addendums to standing DUAs that establish the public health purpose, duration, and use of the surveillance.

As SyS is a near-real time data source and commonly used in public health preparedness and emerging threat detection/quantification, the process should be equally expedient and predictable. In other words, **the process for agreeing to share data with another site or CDC program should be tied to the recency and frequency of the data.**

The NSSP Data Sharing Regional Workshops proved that data can be shared in real-world to address public health concerns through its exercises. Projects that deal with defining the legal parameters to efficiently and effectively share data through the platform should be supported with local, state, federal, and association representation to rectify the outstanding barrier to sustained sharing. **NSSP should continue to promote projects that effectively use shared data and continue to make technical improvements to make the process more granular and user-friendly.**

The workshops predominantly focused on site-to-site data sharing. However, there may be an opportunity to further refine the national view in which all sites participate. NSSP and the NSSP Community of Practice should consider increasing the granularity of the national view to at least state-level visibility (as opposed to the current HHS Region). Gradual steps to renegotiate the baseline of data sharing on the BioSense Platform may encourage greater acceptability and utility. More use of the system will encourage greater scrutiny of data quality and better interpretation of results.