

NSSP DATA SHARING WORKSHOP REPORT

West Region



NSSP Data Sharing Workshop West Region



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Executive Summary

The third in a series of four data sharing workshops convened 36 representatives from 12 states across HHS Regions 8, 9, & 10 with a geographical span from Hawai'i to the Dakotas. The workshop was designed and facilitated by Kahuina Consulting, LLC to guide participating jurisdictions on a structured path of realizing the value of data sharing, appreciating the value, and utilizing that value through continued regional projects that rely on or promote access to shared data in the BioSense Platform. The process was participant-driven with tangible exercises designed around evaluating and using a shared standard classifier on shared data with a common tool: BioSense ESSENCE.

The West contains a mix of highly experienced syndromic surveillance analysts with very mature systems and states that have yet to develop a syndromic surveillance system or submit data to the BioSense Platform. There was also strong community leadership represented at the West workshop through the chair of the NSSP Community of Practice, technical workgroup chairs, and the CSTE Surveillance and Informatics Steering Committee Chair. The workshop concluded with five mini-projects focused on tangible short-term outputs, with two of the projects working on processes and agreements for data sharing, one developing regional surveillance products (dashboards and alerts), one exploring data quality interpretation, and a specific California project to increase the utility of BioSense in the state.

The activities on the first day for opioid (and other illicit drug)-specific use cases had different interpretations based on the public health agency; local jurisdictions were more apt to consider individual case follow-up, while state agencies were considering trends and potential cross-border health seeking behavior. This difference illustrates how public health response and action will vary depending on the authority and responsibility of the public health agency when an alert of increased drug- and/or opioid-related overdoses are observed.

The standardized process and DUA template could be further leveraged by NSSP. There is a strong willingness and readiness to share data – however, sites need some structure and standardization to the process. Utilizing the opioid epidemic as an initial use case to implement this approach will allow the NSSP, CSTE, syndromic surveillance program managers/analysts, and ESOOS grantees to leverage the current public health emergency to highlight the need for a cross-border coordination for an epidemic with no regard for jurisdictional boundaries. Leveraging the energy of the community leadership in this region will also benefit the continued development of solutions to increase consistent data sharing in BioSense.



Background

The West workshop was the third in a series of NSSP regional data sharing workshops. The objectives, design, and delivery are consistent across the four national workshops. The West workshop was the largest of the four, necessitating changes in the program delivery, including extending the time available to charter their mini-projects. There was a wide distribution of BioSense participation, local and state public health agencies, and leaders from the NSSP Community of Practice. Four of the participating states (CA, CO, HI, and SD) do not contribute data to the BioSense platform; local jurisdictions do submit data in CA and CO.

The activities for all workshops are centered on Enhanced State Opioid Overdose Surveillance (ESOOS) funding priorities, specifically to increase the timeliness of surveillance of non-fatal overdose related events. Kahuina utilized five syndrome classifier definitions developed by the CDC with syndromic surveillance community input (All Drug, Heroin, Opioid, Stimulant, and Suicide). The design of the workshop allows participants to rapidly evaluate the query definition and apply those definitions to shared data in the BioSense environment. Mini-projects that utilize these query definitions are chartered to continue exploring the utility of shared data on overdose surveillance, including baselining for situational awareness, reporting, and initiating a public health response.

Workshop Description

This regional workshop engaged state and local jurisdictions from HHS Regions 8, 9, and 10 in a three-part process: pre-workshop design calls, the facilitated workshop, and a post-workshop follow-up call. A pre-call assessment was delivered to gauge current self-identified experience with syndromic surveillance methodologies, system functionality, and current sharing with CDC programs and other jurisdictions. Additionally, the pre-workshop assessment asked participants to share their expectations for the workshop and what areas they wanted to explore related to shared data and the intersection with the opioid epidemic.

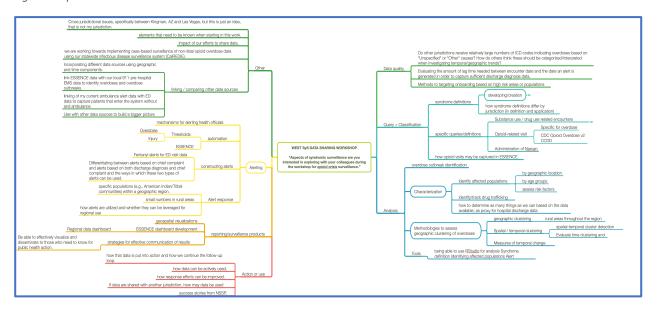
This workshop represents the largest group with 36 participants from 12 states and eight local public health agencies. They represented over 300 years of combined public health experience, yet more than half reported limited to no experience using BioSense ESSENCE. The participants described their goals for the workshop as the following:

- Strengthened relationships with colleagues;
- Developing actionable plans for data sharing; and
- Improved technical competency on shared tools and data quality analysis.

Figure 1 illustrates the specific interests the participants provided for opioid surveillance. These interests were categorized with data collection, classification, analysis, alert thresholds, and use of the surveillance as the main groupings. In the analysis grouping, there was specific reference to identifying small-area geographies and clusters across state borders.



Figure 1. Opioid Surveillance Interest

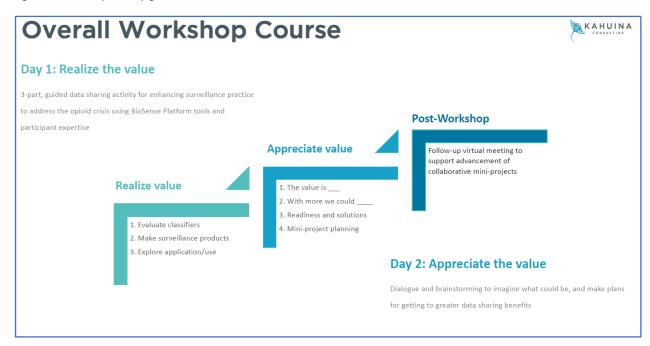


Kahuina used these groupings to modify the data sharing activities delivered during the in-person workshop. The activities are described below and were presented to the participants during the second design call. All BioSense participating sites, with the exception of Idaho, shared aggregated data for patient and facility location. Idaho was unable to share data through the BioSense platform due to explicit wording of their data use agreements with facilities. Tri-county, Colorado was able to provide user accounts to their colleagues from the Colorado state health department, and, Hawai'i and South Dakota participated without an account or data in BioSense.

The in-person workshop was delivered over two days – Day 1 focused on realizing and appreciating the value of shared data, and Day 2 focused on aspiring for greater data sharing with concentrated work on mini-projects.



Figure 2. Workshop activity goals



Data Sharing Activities

The Day 1 data sharing activities were designed to explore the syndrome classifiers developed for drug-related injury surveillance and the functionality of the BioSense Platform ESSENCE application. Participants were divided into five groups (roughly seven people per team) with a mix of experienced and novice syndromic surveillance users. The day was structured around two activities that were designed to encourage teamwork using shared data and the BioSense Platform suite of tools.

Activity 1

Each team was assigned a syndrome classifier to evaluate using community-defined standards and the CCQV data set in BioSense ESSENCE. The five classifiers explored were the CDC-developed All Drug Overdose, Heroin, Opioid, Stimulants, and Suicide classifier definitions. The teams then evaluated the information being returned through the CCQV data set and applied the classifiers to the workshop shared data set.

This activity provided an opportunity for experienced ESSENCE users to guide novice users through the steps of accessing the queries, understanding query definitions, realizing some of the unique functionalities of the BioSense ESSENCE tool to review the de-identified CCQV data, and experiencing how to run Chief Complaint and Discharge Diagnosis defined queries. There were some participants that had no exposure to syndromic surveillance methodology and very little epidemiology experience.

The size of the teams in this workshop started to expose some challenges with this approach. There were several experienced users that appeared to be more interested in advancing their specific work rather than promoting syndromic surveillance methodology to novice users.



Each team was then asked to report back to all participants on the syndrome they evaluated, the public health importance of the classifier, and necessary information needed to interpret the results of the classifier.

Participants were asked to clearly state the public health importance of the overdose surveillance. This intentional prompt was designed to build the foundation for why the surveillance was being conducted. The mix of local and state jurisdictions provided more concrete action compared to the enhanced situational awareness identified at the previous workshops. This included using the surveillance for case identification and follow-up as well as evaluating the effectiveness of public health interventions (for example, a decrease in syndrome-specific ED visits following an intervention).

Activity 2

The second data sharing activity was focused on the development of surveillance "products" (i.e., trendlines, maps, dashboards, and alerts) based on the evaluated syndromes. Teams 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 those products with other BioSense ESSENCE users. During their report out, the teams were asked to consider how this data could be used to inform the prevention and response to the Opioid Epidemic.

Data Sharing Activity Themes

At the conclusion of data sharing activities, several themes emerged in the utility of the available tools and data. None of the teams suggested changes to the syndromes, reinforcing a trust in the process used to develop those syndromes with sufficient documentation. The process of systematically reviewing a shared syndrome definition (examining the purpose, logic, and inclusion and exclusion terms) should help with real-world acceptance of a new syndrome for an emerging threat. Participants again placed a strong emphasis on communication between sites and affiliated public safety agencies.

Working with colleagues across jurisdictional borders fostered some of the connections needed for improved communication. Additionally, participants benefitted from CDC super users providing their experience in using the ESSENCE tool and AMC interface to answer several functionality questions of the BioSense Platform. The interpretation of and action on shared data still needs to be explored – however, the states that aren't currently participating in BioSense expressed value in the information and the system.

The ability to share analytics between sites and users was highlighted by less experienced users and some of the local jurisdictions in California with limited resources to dedicate to syndromic surveillance. Participants were excited by the ability to share a dashboard through BioSense ESSENCE. Some caution should be exercised to ensure that the receiving participant understands the analysis being shared; however, this functionality leverages expert user knowledge from any site for the benefit of the syndromic surveillance community.



The aggregated data details seemed to be sufficient for the use cases described. Some of the local jurisdictions expressed a need to have more granular shared data to perform outreach and case identification, yet this may be limited to configurations like those in California and Colorado (i.e., the local jurisdictions are site administrators and the state health department has limited coordination of the shared data). For example, local California sites need to share data between each other to produce a comprehensive view of the state. Once the potential for this comprehensive view became evident, it spurred conversations on how to increase the representativeness of the data. California sites concluded that they could increase the coverage rate of ED visits in California by onboarding the largest healthcare system in the state.

Affinity Grouping

In order to provide more time to work on the mini-projects, the value and aspiration of data sharing was split between Day 1 and Day 2. Affinity grouping was used to categorize the responses to several questions. After each question, participants were given a short amount of time to fill in the blank on individual post-it notes. The post-its were then categorized into themes by the participants, and each person was asked to verbally elaborate on their ideas.

Following the data sharing exercises, participants were asked to describe the value of data sharing by completing the following statement:

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

Several individuals were named in this first exercise reinforcing the collaboration and teamwork exhibited during the data sharing exercises as well as the continued need for knowledge transfer and methodology sharing between users.

Participating in a practical syndromic surveillance activity using the BioSense platform encouraged non-submitting jurisdictions (CA, CO, HI, SD) to advocate for leadership buy-in. Participants from Colorado State were encouraged by the expertise demonstrated by their local jurisdictions. South Dakota and California both expressed a desire to improve their ED visit coverage by onboarding large health systems.

At the end of Day 1, a poll was started to collect emerging ideas for mini-projects.

Day 2 began with establishing the aspirations of the group by asking the following question and grouping the responses as described above:

"With more sharing and collaboration, we could	·"
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The resulting categories were focused on improving the efficiency of public health surveillance and response. There were commonalities in decreasing duplication of effort by sharing knowledge and solutions. This goal is grounded on establishing and maintaining trust between sites. Specifically, participants expressed a desire to have analytics and visualizations shared among sites allowing for more time to interpret the results and gain a greater understanding of the burden on affected populations in the region.



There was a slight departure from the two previous workshops as the group prepared to identify and charter their projects. Each site was asked to validate their data sharing readiness, illustrated in Figure 3, assuming that the discussion was limited to sharing on the BioSense Platform for a defined project between other sites and/or CDC programs. The majority of participating jurisdictions are ready to or actively sharing a minimum of aggregated data through the BioSense Platform with CDC programs and other sites.

Figure 3. Self-reported data sharing categorization

Steward	BioSense Platform			Sharing With CDC Programs		Sharing With Another Site	
	Data	Fc. Agmnt.	Admin	Line Level	Aggregate	Line Level	Aggregate
AZ	Yes	Yes	Yes	Willing	Ready	Willing	Ready
AZ Marricopa	Yes	No	No	Willing	Ready	Willing	Ready
AZ Pinal	Yes	No	No	Willing	Ready	Willing	Ready
CA	Unsure	Unsure	No	Unknown	Unknown	Unknown	Unknown
CA Riverside	Yes	Yes	Yes	Willing	Willing	Active	Active
CA Sacramento	Yes	Yes	Yes	Ready	Ready	Ready	Ready
CA San Mateo	Yes	Unsure	Yes	Unable	Willing	Unable	Willing
CA Yolo	Yes	Yes	Yes	Unable	Ready	Unable	Active
со	9999	9999	9999	Unknown	Unknown	Unknown	Unknown
CO - NCR	Yes	Yes	Yes	Ready	Active	Ready	Ready
н	Planning/ deciding	Unsure	Unsure	Unknown	Unknown	Unknown	Unknown
ID	Yes	Yes/unsure	Yes	Unknown	Unknown	Unknown	Unknown
NM	Yes	Yes	Yes	Unknown	Active	Willing	Willing
ND	Yes	Yes	Yes	Unknown	Willing	Unknown	Willing
NV	Yes	Unsure	Yes	Willing	Active	Willing	Willing
OR	Yes	Unsure	Unsure	Active	Active	Ready	Ready
SD	9999	9999	9999	Unable	Willing	Unable	Unable
UT	Yes	Yes	Unsure	Active	Active	Ready	Ready
WA	Yes	Yes	Yes	Active	Active	Unknown	Active

With this table validated, the participants were asked to review the *Public Health Data Sharing: Barrier Taxonomy*¹ and discuss potential barriers in small groups that may still be preventing active data sharing. However, groups were not asked to report out on the barriers; participants were asked to respond to the following statement:

"	will	get	me	full	v sh	aring	."

The responses to this statement were combined with additions from the poll posted the previous day for project ideas. Reviewing and discussing the *Barrier Taxonomy* may have influenced responses towards defining political and legal processes and mechanisms to ensure DUA coverage. The participants then grouped their responses into potential projects to be voted on. During the classification exercise, California sites asked to be given time to specifically work on improving BioSense utility in their state.

¹ 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.



Project Initiation

Participants self-selected into five groups to charter a project continuing and begin working on identified deliverables. The projects included:

- 1. Process for syndromic surveillance data sharing Define a workflow and process for data sharing requests.
- 2. Data quality for inter-jurisdictional data sharing Define a standard workflow to understand data quality of shared data.
- 3. DUA template Develop a model data use agreement inter-jurisdictional data sharing.
- 4. Model Inter-jurisdictional dashboard Develop a shared inter-jurisdictional dashboard in BioSense ESSENCE for a variety of surveillance use cases.
- 5. California county BioSense participation Increase the number of counties participating in BioSense and sharing data within the state.

The participants were given several hours to document the idea, define the project, and commit to initial deliverables/milestones. A follow-up call was scheduled for two weeks after the workshop to 1) ensure initial work had continued outside of the workshop and 2) hold the participants accountable to continuing the work.

Each group presented their refined project charter on the follow-up call. The majority of the groups had done very little since the workshop, with the exception of the California mini-project. Despite the number of community leaders that participated in the West regional workshop from the NSSP Community of Practice, teams reflected that there was a lack of leadership within the projects. This may be due to a misplaced disconnect between the regional workshops and ongoing NSSP Community of Practice Committees.

The effect of the sunsetting of the International Society of Disease Surveillance (ISDS) was evident in this workshop. One proposed project (that was not chartered) focused on knowledge management and the convening organization for project outputs. The lack of certainty around how this work will be incorporated into the overall body of syndromic surveillance practice and NSSP programming is a lingering concern.

The California BioSense utilization mini-project catalyzed a conversation with the California BioSense User Group to identify every county in the state that is submitting to the system and engage large counties with existing systems (like Los Angeles and San Diego) to onboard. A preliminary use case for influenza-like illness surveillance is being established to encourage counties to share data for state-wide visualizations. The team will also use this work to re-ignite conversations to on-board large private facility networks in the state.

The success of the groups in completing these projects will be dependent on a convening organization, like CSTE, to hold them accountable for the project deliverables. A concerted effort to harmonize the outputs from the workshop projects with the existing NSSP Community of Practice and the organization that succeeds ISDS will be important with the West group to ensure buy-in from community leadership. As the workshops conclude, there are similar groups emerging that could be transitioned to national



working groups (regional dashboarding and cross-border data analysis/quality). There are also groups that may be benefit from the work of others. For example, the leadership communication toolkit may help the California team (as well as CO and HI) to present the value proposition to other jurisdictions and their decision makers.

Conclusion

The West Regional Workshop provided a valuable opportunity for a diverse mix of syndromic surveillance analysts, program managers, and Community of Practice leadership to convene, actively share data through the BioSense Platform, and manipulate shared analysis using the BioSense ESSENCE environment. The participants were given more time to work together on their mini-projects. The chair of the NSSP Community of Practice attended (and hosted the workshop at her agency) with a desire to continue this work outside of the workshop. Every BioSense participating jurisdiction in attendance was able to share data and focused on the components of how to standardize a process to initiate and maintain project-specific data sharing. Two of the mini-projects are specifically looking at the process steps to share data and the content of a DUA, if needed. The California project will most likely benefit from projects chartered in other workshops, including the leadership communication toolkit and the site onboarding assistance group, as they prepare to increase the coverage and utility of BioSense in their state.

Only one of the mini-projects is actually focused on the use of shared data – however, the intent is to create a model dashboard that can be easily configured in other jurisdictions. The shared dashboard could work with either shared or local data. In either example, public health practice is improved by fostering continued relationships between novice and expert users. This project is focused on an opioid surveillance use case but can easily be customized to an all-hazards approach.

As identified in the other workshops, a significant skill and resource gap was clearly evident due to the size and diversity of representation in the West workshop. Larger and better resourced public health agencies have greater flexibility in dedicating staff to specifically focus on syndromic surveillance. All states should be able to resource these positions with the inclusion of syndromic surveillance funding in the upcoming ELC grants; however, the skill gap between early and late adopters of syndromic surveillance may remain.

Creating pre-formatted and structured surveillance products to be shared across a region (or nationally) may help bridge the skill gap by leveraging the expertise of more experienced syndromic surveillance epidemiologists and analysts in public health agencies, including the CDC. However, users receiving these products still need to understand the entire process from data collection to visualization in order to properly interpret the results. The schism in skill provides an opportunity to consider additional tiered training for beginner, intermediate, and advanced syndromic surveillance / BioSense ESSENCE users.

The timing of data sharing for a particular use case is a critical component of the process that is being defined in one of the mini-projects. The process should be minimally invasive with a turnaround time equivalent to the recency of the data. For example, in a syndromic surveillance system that relies on daily data, the process for agreeing to share data should not take more than 24 hours.

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Comfort with the technology is growing – there was general acceptance of the data that was shared by other sites through BioSense and the shared syndromes used to produce the surveillance products. Of the sites that responded, none expressed an explicit prohibition (or permission) to share data, and several sites are actively sharing data. The often-cited legal barriers may be more political. Therefore, the process of activating data sharing for a specific use case may be more necessary than a formal DUA. Caution should be taken to avoid over complicating data sharing with onerous legal documentation unless expressly required.

Some issues will need to be resolved within the structures of state and local governments. For example, a large local jurisdiction that falls under a state site administration may wish to share data with other sites, yet lacks the ability to do that without state approval. The Community of Practice, NSSP, and CSTE have an opportunity to highlight best practices of local, state, and CDC programs rapidly sharing data for a specific use case. System functionality to support a more granular and nuanced governance structure for large local jurisdictions may be required, especially for home-rule states.



Annex A: Agenda

CSTE Regional NSSP Syndromic Surveillance Data Sharing Workshop

West HHS Regions 8, 9, 10

Facility/Location

Arizona Bureau of State Laboratory Services

250 N 17th Avenue Phoenix, AZ 85007

Purpose

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.

Workshop Objectives

By the end of this meeting, participants will have...

- 1. Enhance syndromic surveillance skills to better support agency activities for opioid crisis response
- 2. Examined and shared best practices in SyS analytic methods and NSSP tool use
- 3. Developed action steps for establishing or strengthening interjurisdictional data sharing
- 4. Fostered collaborations among the peer network of surveillance professionals

Agenda and Schedule

Day 1: Tuesday, July 23rd – Discovering the Value of Data Sharing

8:30 AM	Participant arrival and set-up
	For one hour before the start of the workshop, participants should arrive to connect
	devices to the facility WiFi, set-up data sharing for the workshop, and take online
	syndromic surveillance skills inventory (if haven't already).
9:00 AM	Welcome and introductions

Wedstern Balane Comment

Workshop kicks-off promptly with a warm-up and welcoming remarks from CSTE and NSSP leadership.

9:30 AM Orientation and overview

A review of the workshop course to orient participants toward a shared set of objectives and confirm expectations.

10:00 AM Sharing activity – Part 1: Classifier evaluations

Guided collaborations in breakout groups to evaluate syndrome classifiers for Opioid Overdose, All Drug Overdose, Suicide, and Heroin Overdose using BioSense Platform tools. By the end of this session, each group will produce an evaluated classifier for use in Part 2.

12:00 PM Lunch break

After each breakout group debriefs their Part 1 work, participants break for lunch and

refreshment.

1:00 PM Sharing activity – Part 2: Analytics, visualizations, and application or use



Breakout collaborations continue to develop ESSENCE products for visualizing analyses of the four syndrome classifiers evaluated in Part 1. Groups also identify ways to apply or utilize the products. By the end of this session, each group will produce a minimum of two products (e.g., myESSENCE Alerts or Dashboards) to share and discuss with workshop collogues.

4:00 PM Data Sharing value and potential

Identify and document participant perceptions of the value proposition for SyS data sharing.

5:00 PM Day 1 Summary & Day 2 Preview

Workshop facilitation team recap the accomplishments of Day 1, check-in with participant satisfaction, and preview Day 2.

5:15 PM Adjourn

Workshop adjourns for the day to reconvene at 9:00 AM on July 24th

7:00 PM Optional: Organized Dinner – Canyon Café

An optional dinner for workshop participants and sponsors to socialize in a casual setting.

Day 2: Wednesday, July 24th – Appreciate Data Sharing Value with Collaborations

9:00 AM Reconvene

Review agenda and schedule for the day and reflect on lessons learned and ideas for post-workshop collaborations.

9:30 AM Data sharing readiness

Review the state of participant readiness for data sharing and identify and explore solutions through a facilitated discussion.

10:30 AM Mini-project formation and chartering

Participants identify and document project ideas, form project teams, and outline project purpose, objectives, deliverables and timeline to share with workshop colleagues.

11:15 AM Charter reviews

Participants share project charters with workshop colleagues for constructive feedback and coordination.

12:15 PM Working lunch and break

Participants break for brief lunch and refreshment, and work in mini-project groups to advance project work.

2:00 PM Progress and next steps

Project groups brief workshop colleagues on progress and describe the next step for completion by the follow-up call.

2:30 PM Workshop summary and conclusion

Workshop facilitation team recap, workshop accomplishments and next steps, and participants and sponsors share parting thoughts.

3:00 PM Conclude workshop

Workshop ends. All are asked to complete a post-workshop skills assessment no later than COB Thursday, July 25th.



Annex B: Data Sharing Activity Instructions

PURPOSE

The purpose of this hand-out is to guide you and your team through a syndromic surveillance classifier (or syndrome) evaluation process, as well as facilitate team work and peer-to-peer learning.

As a team, complete each task in sequence. The tasks are written for you to problem solve and learn from one another's expertise and knowledge. Your team should determine how you go about completing the work based on the instructions. Most importantly, have fun and enjoy this opportunity to discuss surveillance science and public health practice with one another.

OBJECTIVES

Evaluate your team's assigned classifier using BioSense Platform tools by completing the following tasks. At the end of this activity, each participant should be able to...

- 1. describe the classifier's scope and purpose,
- 2. identify evaluation guidelines,
- 3. describe the rationale for making or not making refinements, and
- 4. possess a rudimentary ability to manipulate the tools and resources available on the BioSense Platform.

ACTIVITY TASKS

- 1. Form your team.
 - a. Acquaint yourself with your new team members with (re)introductions (e.g. name, job/role, workplace, something about their syndromic surveillance system).
 - b. Read this entire document to ensure every team member knows what the team should accomplish during the activity.
 - c. Assign the following team roles.
 - Operator responsible for projecting their desktop and running ESSENCE or other BioSense Platform application(s) for your team throughout the activity



- Recorder responsible for keeping notes on your team's discussions and help share the team's work with the other teams
- Reporter responsible for presenting your team's findings to the other teams at the end of the activity
- Time keeper responsible for ensuring that the team is aware of the activity's elapsed and remaining time
- 2. Define the <u>public health purpose</u> of surveillance using your assigned classifier/syndrome. Be sure to discuss and note the team's discussion on each of the following:
 - a. The public health concern related to the opioid-crisis
 - b. The approximate likelihood that the syndrome is present in emergency department (ED) visit data
 - c. What added insight(s) may be gained by trends in this syndrome across shared inter-jurisdictional data
- 3. Define the **scope of syndromic surveillance** using the classifier on ED visit data. Be sure to discuss and note the team's thoughts on each of the following:
 - a. Purpose or intention: The public health question(s) to be answered by the surveillance, and associated planned or possible action(s)
 - b. Relative priority of sensitivity versus specificity
 - c. Time frame for surveillance and observation
 - d. Inclusions or exclusions to the data given the above; e.g., facility or visit types, etc.
 - e. Additional or supplementary data sources; e.g., EMS, 911, poison control center, etc.
- 4. Review your team's assigned classifier's definition and discuss the results that one might find when it is performed or queried against ED visit data.
- 5. Using BioSense ESSENCE, examine the classifier's performance and determine whether and how it might be refined for better performance. Suggestion: consider doing one or more of the following as time allows.



- a. Execute the classifier as a query against the **CCQV dataset** and **shared** workshop dataset.
- b. Review query results at line-level and in visualizations; e.g., time-series.
- c. Roughly identify keywords that drive results by percentage of probable records captured per classifier terms or term combinations.
- d. Gauge the proportion of suspect or probable syndrome-visits captured, or missed, by the classifier query.
- 6. If classifier's performance can be improved, make the appropriate component changes, and save and share it with your team using the BioSense ESSENCE *Query Manager*.
- 7. Discuss and note your team's thoughts on how the classifier should be used at local, state, regional and national levels. Be sure to identify and address interpretation differences at the different levels and document additional information needs to interpret the results.
- 8. Prepare a 5-minute report-out to share your team's key findings with the other teams. Assist your team reporter to prepare 1 or 2 slides that address the following questions:
 - a. What is your team's definition of the public health concern, and how does that relate to the classifier's surveillance scope and purpose?
 - b. Why did your team change or not change the classifier? If it was changed, how does it differ from where you started?
 - c. What caveats or other descriptors should accompany this classifier to help with the interpretation of results?
 - d. What public health action would your team propose from a surveillance signal?



Activity 2: Classifier Analysis and Visualization

OBJECTIVES

For the classifier you evaluated in Activity 1, create and share surveillance products using BioSense ESSENCE on the BioSense Platform by completing the following tasks. By the end of this activity, each participant should be able to...

- 1. utilize a shared data set for syndromic surveillance analysis;
- 2. create, save, and share timeseries dashboards,
- 3. create, save, and share geospatial dashboards, and
- 4. create, save, and share myAlerts in the BioSense ESSENCE environment.

TASKS

Review the instructions. This activity is designed to create ESSENCE products that query the shared workshop dataset and are then shared with all team members. Be sure you understand what needs to be accomplished before proceeding.

- 1. Assign the following team roles.
 - a. Operator responsible for projecting their desktop and running ESSENCE or other BioSense Platform application(s) for your team throughout the activity
 - b. *Recorder* responsible for keeping notes on your team's discussions and help share the team's work with the other teams
 - c. *Reporter* responsible for presenting your team's findings to the other teams at the end of the activity
 - d. *Time keeper* responsible for ensuring that the team is aware of the activity's elapsed and remaining time
- 2. Confirm with each team member the data they are sharing for the workshop to help facilitate interpretation of results: e.g., facility location and/or patient location and level of granularity.
- 3. Define the question(s) you want to answer, and for what audience, with the surveillance products (e.g. analysis and visualizations) you'll make during this activity.



- 4. Apply the assigned classifier to the shared data set and describe the results, answering the following questions:
 - a. Stratify the results by geography, age group, gender, and race/ethnicity (if available). What segment of the population is most affected?
 - b. What additional data granularity or information do you need to further explain your surveillance and the population?
- 5. Create a time series and geospatial dashboard to describe the population health trends; share it with your team members through BioSense ESSENCE.
 - a. Describe any trends, clustering, alerts, or anomalies.
 - b. Are any known events from your community or surveillance notable?
- 6. Create a myAlert in BioSense ESSENCE based on your surveillance; share it with your team members.
 - a. What alert thresholds were chosen for the surveillance?
 - b. Identify any signals in the shared data that are *not* identified in individual data sets.
- 7. Discuss the interpretation of your analysis with the team and consider the following additional points:
 - a. Use the list of HIDTA counties to evaluate if there is a correlation between increased visits and HIDTA-designated counties.
 - b. Describe any data quality, including representativeness and completeness of the data, that affects your team's interpretation.
 - c. Describe any concerns arising from analyzing the shared data.
 - d. Develop at least three executive-level (state epi or higher) talking points that conclude the surveillance.



- 8. Prepare a 5-minute report-out to share your team's key findings with the other teams. Prepare the team reporter to display and explain your surveillance products.
 - a. What question(s), and for whom, is your product designed to answer?
 - b. What is your answer to the question(s) given the insights gained?
 - c. What could your audience do with the insights informed by your surveillance?
 - d. What were the major challenges identified that would prevent you from using the shared data or analysis?



Annex C: Collected Legal Language

QUESTION POSED

Is inter-jurisdictional sharing permitted or barred under a formal agreement or public health authority or informal agreement? Please provide a copy or hyperlink to the relevant legal agreements (i.e., templates), laws, rules, or other.

RESPONSES

California

Neither expressly permitted nor barred.

Riverside County, CA

Neither expressly permitted nor barred.

Sacramento County, CA

Neither expressly permitted nor barred.

San Mateo County, CA

Neither expressly permitted nor barred.

Yolo County, CA

Neither expressly permitted nor barred.

South Dakota

Neither expressly permitted nor barred.

Utah

Neither expressly permitted nor barred.



Annex D: Mini-Project Charters

1. Process for syndromic surveillance data sharing

Project Members: Greg, Eunice, Melinda, Mitch, Teresa, Kirk

Purpose:

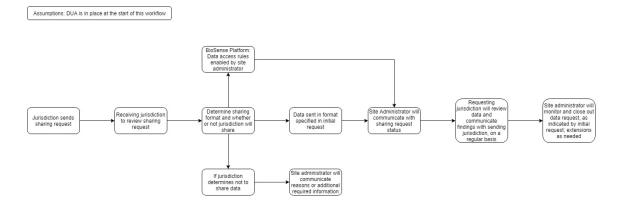
Assuming a DUA is in place, determine a procedure for shared data handling including the request and closing processes, stakeholder engagements, and communication pathways.

Deliverables:

- 1. Create a basic workflow and further define each process for each sharing request
- 2. Create a standardized form for data sharing requests including:
 - a. How the data will be used
 - b. Data description and other details related to data governance
 - c. Format for sharing (dashboard and aggregation details, other data visualization options, etc.)
 - d. Timelines
 - e. Data suppression including interstate considerations
- 3. Communication pathways and contact lists for stakeholder engagement

Tasks in the next two weeks:

- 1. Review data sharing resources available on the knowledge repository
- 2. Review and assess DUA with facilities as a model for inter/intra jurisdictional data sharing
- 3. Check in with CDC about how data access rules are set up in the BioSense platform and to what granularity (can we specify a timeline and is it per user or per jurisdiction?)
- 4. Determine platforms and interest from participating jurisdictions
- 5. Finalize basic process diagram
- 6. Explore possibility of oversight committee to ensure data is used appropriately workgroup?





2. Data quality for inter-jurisdictional data sharing

PROJECT MEMBERS

Sara Chronister Krystal Collier Levi Schlosser Michael Sheppard Loren Rodgers Sebastian Romano

PURPOSE

Provide jurisdictions a standardized workflow for understanding data quality and data considerations across jurisdictions leading up to data sharing.

DELIEVERABLES

- 1. Question guide for jurisdictions to follow to share information about their data
- 2. Evaluation of question guide

TASKS

- 1. Identify a workgroup to assemble the question guide and assign roles for the project
- 2. Categorize the types of questions that need to be included in the guide
- 3. Identify existing tools that can be adapted for the purpose of answering questions in the guide
- 4. Create a theoretical use case to guide how the question guide is created and utilized

3. DUA template

PROJECT MEMBERS:

Jessica White
Keaton JHughes
Kate Goodin
Kathy Turner
Mandy Nakamura
Derek Vale
Lori Zigich
Rasha Elnimeiry
Nick Hill

PURPOSE:

Develop a model data use agreement for sharing between jurisdictions and associated resources



DELIEVERABLES:

- FAQ and instructions
- Template with annotation
- Inventory of data use agreement execution and status
- Recommended stakeholder communication plan
- Recommended governance of DUAs

TASKS:

- Develop implementation plan for template development (process, timeline, etc.)
- Collect existing DUAs in use by jurisdictions that they think are useful and helpful
- Identify common components and what components can be adapted / tailored
- Identify what relationships would be considered in data sharing (state to state; state to local; state to federal)
- Identify how the DUA template will be reviewed and updated in an ongoing way

Tasks to complete within two weeks:

- Request to other jurisdictions to obtain opinion or judgements on needs or requirements for data use agreements between jurisdictional levels.
- Request copies of existing data use agreements

4. Model Inter-jurisdictional dashboard

PROJECT MEMBERS

Amanda, Kelli, Rob, Kevin, Carson, Dametreea

PURPOSE

To develop a template dashboard to be implemented with various types of interjurisdictional outcomes

DELIVERABLES

- Template dashboard(s) by facility and/or patient location
 - o Example queries included
 - Example alerts included
 - Multiple widget types (bar charts, time series, maps, etc)
 - Stratifications by site
 - Demographics (age/sex/race/ethnicity)



TASKS

- Develop a modifiable dashboard template
 - Schedule a conference call within the next two weeks (by Jul 7th)
 - o Talk through the template format and key components to include
 - o Assign someone to create the dashboard and share
 - Team review/update of the dashboard
 - o Dashboard "owner" make final updates and re-share
 - o Share template dashboard with regional group

NOTES

- Template should be modifiable to suit various data/outcome needs

5. California county BioSense participation

PROJECT MEMBERS

CDPH – Natalie Demeter
Riverside – Wendy Hetherington/Rick Lopez
San Mateo – Karen Smith/Debbie Van Olst
Sacramento – Karman Tam
Yolo – Haydee Dabritz
CDPH CalREDIE – Tamara Hennessy-Burt tentative?

PURPOSE

Increase number of counties reporting in BioSense

Improve communication LHJs to state

Ensure proper DUAs are in place county-to-county and county-to-state

Engage counties who have their own SyS (San Diego, Santa Clara, L.A., Solano)

DELIVERABLES

- 1. DUAs if needed
- 2. Identify CDPH champion(s)
- 3. Define CDPH role
- 4. Define reporting region (learn from other states, e.g., TX Dept of State Hlth Svcs)
 Landscape analysis of BioSense county onboarding status (not started, planning, new onboard, experienced onboard, own system)
- 5. Contact list for counties for syndromic surveillance (regional contact for LHJs without ED)
- 6. Situational awareness map of all hospitals

TASKS

1. Contact CDPH data guru/R expert Dr. Michael Samuel (Haydee)

NSSP Data Sharing Workshop West Region



- 2. Landscape analysis (county BioSense list) (Natalie)
- 3. Contact counties in BioSense not at training (Haydee)
- 4. Contact Solano (Haydee), L.A. (plus city LHJs) and San Diego counties (Wendy/Rick) re their system
- 5. Hospital map (Karman)