

NSSP DATA SHARING WORKSHOP REPORT

Northeast Region

December 2019

with support from:





Contents

Acknowledgements	2
Executive Summary	3
Background	4
Workshop Description	4
Data Sharing Activities	6
Affinity Grouping	7
Project Initiation	9
Conclusion	10
Annex A: Agenda	12
Annex B: Data Sharing Activity Instructions	14
Annex C: Collected Legal Language	19
Annex D: Mini-Project Charters	20
1. Leadership Communication Toolkit	20
2. NE Region Cross-Jurisdictional Data Sharing	21
3. Regional Alert Network (Sys 911)	22
4. Overdose-related Opioids and Stimulants – Northeast Regional Dashboard	23



Acknowledgements

Kahuina would like to thank the following people and organizations for contributing their time and expertise to the Northeast Regional Data Sharing Workshop.

Workshop Participants

Kristin Soto	Connecticut Department of Public Health
Sara Robinson	Maine Center for Disease Control and Prevention
Jenna Strathdee	Maine Center for Disease Control and Prevention
Rosa Ergas	Massachusetts Department of Public Health
Nomana Khan	New Hampshire Department of Health and Human Services
David Swenson	New Hampshire Department of Health and Human Services
Teresa Hamby	New Jersey Department of Health
Rachel Hammond	New Jersey Department of Health
Shivani Arora	New York Department of Health
Sarah Kimball	New York Department of Health
Charlene Weng	New York Department of Health
Kaamna Mirchandani	Pennsylvania Department of Health
Jonah Long	Pennsylvania Department of Health
Carolyn Malone	Rhode Island Department of Health
Veronica Fialkowski	Vermont Department of Health

Centers for Disease Control and Prevention (CDC)

Breanna Alman	CSELS
Tara Anderson	CSELS
Michael Coletta	CSELS
Taylor Dias	CSELS (ORISE)
Deborah Gould	CSELS
Aaron Kite-Powell	CSELS
Zach Stein	CSELS (CTR)
Antheny Wilson	CSELS

Council of State and Territorial Epidemiologists (CSTE)

Hayleigh McCall Alexis Darden

Kahuina Consulting, LLC

Charlie Ishikawa Heather Head Marcus Rennick

Funding for this workshop was provided through CDC Cooperative Agreement number NU38OT000297-01-00.



Executive Summary

The second in a series of four data sharing workshops convened 15 representatives from nine states in the Northeast across HHS Regions 1, 2, and 3. 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 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 Northeast contains a mix of longstanding historical syndromic surveillance systems and users very skilled in using BioSense ESSENCE. Despite some initial apprehension in what data could be shared, all states were able to share adequate data for the activities with one state (Maine) expressing a policy decision to be generally permissive with data sharing. The workshop concluded with four mini-projects focused on tangible short-term outputs, with two of the projects creating regional surveillance products (dashboards and alerts) and the other two filling a void in protocols on data sharing and communicating the value of syndromic surveillance and shared data with intra-agency leadership.

The first two mini-projects continue the opioid-specific use cases identified during the workshop: specifically looking at drug related overdoses with regional surveillance products and developing a response network to take action when an alert of increased drug and/or opioid related overdoses are observed. There is limited precedent on what a regional or joint response would encompass. Linking the public health action to address the demand side of the opioid epidemic and respond to clusters of overdose activity should be treated as any all-hazards public health preparedness response with close coordination with supply-side actors (law enforcement, public safety, etc.).

The protocols and communication toolkits could be further leveraged by NSSP. The state agency participants were searching for a structured way to feel comfortable that they were sharing data properly. The components of these protocols could form addendums to the current BioSense DUA for specific use cases (both for discrete events and routine surveillance). Utilizing the opioid epidemic as an initial use case to implement this approach will allow the NSSP, ESOOS, CSTE, and the syndromic surveillance program managers and analysts 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. The talking points crafted by the communications projects could facilitate intra-agency discussions with the appropriate decision makers within the state and supported by the CDC and CSTE where appropriate.



Background

The Northeast workshop is the second in a series of NSSP national data sharing workshops. The objectives, design, and delivery are consistent across the four national workshops. Minor changes were incorporated to improve content delivery and facilitation between the South and East workshop and the Northeast workshop. The Northeast is unique among the four workshops due to the absence of local health department representation. Despite historically strong syndromic surveillance systems and invitations, both New York City and Boston were unable to attend.

The activities for all of the workshops are centered on Enhanced State Opioid Overdose Surveillance (ESOOS) priorities, specifically to increase the timeliness of surveillance of non-fatal overdose related events. Kahuina utilizes four syndrome classifier definitions developed by the CDC with SyS community input (All Drug, Heroin, Opioid, and Stimulant). 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 brought state jurisdictions together from HHS Regions 1, 2, and 3 in the similar three forums used in the first workshop: 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 for the 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 smallest group with 15 participants from nine states. They represented over 150 years of combined public health experience with roughly a third identifying as syndromic surveillance beginners. The participants described their goals for the workshop to include:

- 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. There was still significant confusion on how to share and what gets shared through the AMC portal. This required a third call to be scheduled with the CDC to demonstrate how to set up a rule in the AMC. CDC then provided one-on-one consultations with site administrators to set-up the appropriate data sharing rule with the Northeast workshop group. Data sharing was limited to granular facility location (full data details). All sites, except MA, were able to share full details; MA was limited to sharing aggregate data details (limiting drill down to specific records).

The in-person workshop was delivered over two days – j Day 1 focused on realizing the value of shared data, and Day 2 focused on appreciating the value of shared data with the intention of launching participants into sustained projects leveraging shared data.



Figure 2. Workshop activity goals



Data Sharing Activities

The Day 1 data sharing activities were designed to explore the syndrome classifiers developed for drugrelated injury surveillance and the functionality of the BioSense Platform ESSENCE application. Participants were divided into four groups (between three and five people) 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 standards and the CCQV data set in BioSense ESSENCE. The four classifiers explored were the CDC-developed All Drug Overdose, Heroin, Opioid, and Stimulants 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. This was noted as a need for workshop participants from the same jurisdiction to meet prior to attending, especially for syndromic surveillance naïve attendees.

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. Each team recognized the need to form situational awareness within the region to understand the movement of people and illicit drugs across borders. The standard query definitions were regarded as adequate for regional surveillance on shared data to direct public health resources and response to areas of high activity. One team detailed their opioid overdose public health response to include local Naloxone distribution, collaboration with affiliated partners (public safety and law enforcement), and direction of intra-agency strike teams to remove products from communities and ensure harm reduction strategies are in place.

One team benefited from the inclusion of a privacy officer (the only non-epidemiologist in attendance). This team highlighted the need to establish the minimum necessary data elements for shared data to meet the surveillance objective and satisfy privacy and security concerns.

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 Day 1, several themes emerged in the utility of the available tools and data. Of note, consistent communication was noted as a key component of shared data. 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 and AMC interface to answer several functionality questions of the BioSense Platform. 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.

Utilizing the CCQV dataset to evaluate query results may eliminate the need for full data details being shared with other jurisdictions (depending on the use case). Massachusetts' inability to share full data details did not limit their participation in the interpretation of the surveillance products. Time series and maps were still able to be produced with their data; "drill down" functionality was the only limitation. However, the need for access to patient location granularity, as opposed to facility location, has a significant impact on the interpretation of shared data and was quickly highlighted as a need. In fact, the ability to group facilities into a smaller area like county (as opposed to a point location and state level granularity) was forwarded to the ESSENCE development team as a system improvement to better classify facility location data.

Affinity Grouping



Day 2 of the workshop focused on appreciating the value of data sharing through affinity mapping with the entire group. Three questions were asked of the group:

- 1. "_____ was delightful or super useful when you shared data and collaborated with me yesterday."
- 2. "With more sharing and collaboration, we could _____."
- 3. "_____ will get us ready and sharing."

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.

Question 1 elicited several mentions of the community being brought together by the workshop and having time to navigate the system with experienced users. The Northeast region has several robust legacy systems, and despite providing data to the BioSense Platform, not all site administrators and analysts were familiar with the changes and enhanced capabilities – including the ease of sharing data. There were several moments of sudden insight or discovery exclaimed regarding the system capabilities and ease of sharing data and analyzing other jurisdictional data.

Question 2 provided participants the opportunity to explore the potential that data sharing has to their work and their population's health. There was a strong convergence around being able to respond to public health events sooner and more collaboratively. Some reflections centered around the differences in submitted data. For example, New York state does not submit discharge diagnosis data. However, more sharing and collaboration could provide the push for a state to improve data completeness or enforce greater compliance with messaging guides from their submitting facilities. Enforcement of data quality may also benefit by having other users utilizing and interpreting a state's data.

Question 3 elicited several categories to explore moving states into being fully ready to share. Ideas to solidify sharing centered on having more conversations or having more detail on site-level agreements to satisfy lingering privacy concerns with addendums for specific use cases. This is despite most states responding that they had no specific rules or regulations that would prevent them from sharing syndromic surveillance data. One state submitted the CDC BioSense DUA as an example limiting sharing data across jurisdictions, while another submitted their state public health privacy regulations as a reason to prohibit data sharing despite its similarities to federal HIPPA regulations with explicit exceptions for public health surveillance.

This confusion on what is allowed to be shared and who makes that decision coalesced on a communication gap, specifically a gap in communicating the value of and an understanding of what states do with syndromic surveillance data between the analyst and leadership. A communications toolkit with talking points to steer a conversation and demonstration of BioSense with program managers and leadership, including embedded security features, quickly floated to the top of the projects list.

The figure below illustrates current data sharing (as reported by the participants) related to CDC and other jurisdictions. As shown, most sites are at least willing to share, if not ready and actively sharing. Maine is actively sharing data across the spectrum due to an open data policy in the state and policy driven decisions to liberalize data sharing within the state. Further discussions with Maine could



illuminate the potential for other states to share data through policy stances. Rhode Island did not complete the pre-workshop survey, and the workshop participant was an alternate to the planned attendees with limited knowledge on current SyS data sharing.

	Sharing With CDC Programs		Sharing With Another Site	
	Line Level	Aggregate	Line Level	Aggregate
ст	Ready	Ready	Unable	Willing
МА	Unable	Active	Unable	Ready
ME	Active	Active	Active	Active
NH	Willing	Active	Unk	Ready
NJ	Active	Active	Willing	Willing
NY	Willing	Willing	Willing	Willing
PA	Active	Active	Ready	Ready
VT	Unable	Active	Unable	Willing
RI	Unk	Unk	Unk	Unk

Figure 3. Self-reported data sharing categorization

Project Initiation

Finally, participants self-selected into four groups to charter a defined project continuing the collaboration built during the in-person workshop. The projects included:

- 1. Leadership Communications Toolkit Develop a slide deck and talking points for SyS program managers to advocate data sharing to executive leadership.
- 2. Cross-jurisdictional data sharing Define parameters and best practices for cross-border data sharing.
- 3. Regional Alert Network Identify meaningful clusters within the region and communicate alerts.
- 4. Regional Overdose Dashboard Develop a shared regional dashboard in BioSense ESSENCE for opioid and stimulant overdose surveillance.

The participants were given a short amount of time 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. All groups communicated with each other prior to the call (which may have acted as the catalyst to refining the charter and agreeing on deliverables). We asked participants to identify the resources needed to continue their work, and the overwhelming response was for logistical and administrative support to convene the groups on a regular schedule and to provide the conference line.

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. The small groups are the foundation of



a community of practice that requires a convening force to maintain momentum and deliver community-led priorities. As the workshops conclude, there may be similar groups that can be merged into national working groups (regional dashboarding and cross-border data analysis). There are also groups that may be unique to a workshop, but with national appeal. For instance, the Leadership Communication group could be adopted as a national communications project that assists site administrators with communicating the value and need to share data through the BioSense Platform.

Conclusion

The NE Regional Workshop provided a valuable opportunity for a diverse mix of SyS 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 pain points that were highlighted in Day 1 as caveats for data sharing (incomplete variables and different or unknown data submission from different sites) did not significantly factor into the projects that were chartered. Three out of the four mini-projects are related to specific uses of continued data sharing: alerting, dashboards, and sharing protocols. The understanding is that the groups will continue with surveillance of shared data and compensate for differences in the data through interpretation.

All participants with data in the BioSense Platform actively shared patient and facility location with the workshop's user group during the workshop. Massachusetts was only able to share aggregate data – however, this did not materially affect the workshop. The CCQV data set and standardized national classifier definitions may limit the need for line-level data. For example, a neighboring jurisdiction may not need to see another jurisdiction's patient-level records if the shared definition is trusted and chief complaints and discharge diagnosis can be evaluated on the CCQV data. This need will, however, differ based on the use case. The Northeast workshop participants were particularly interested in defining the parameters of a surveillance use case that would warrant shared data.

These specific use cases could be introduced through the BioSense Platform as opt-in data sharing surveillance projects. The scope of the project could include the intended use and duration of the surveillance and what granularity of data needs to be shared. As sites opt-in to these projects, an automatic addendum to their CDC DUA could be added. This may help alleviate some of the continued legal barriers to sharing.

However, most of the participating states do not have express prohibitions on sharing data for public health surveillance. Ambiguity over what can be shared and a lack of realized authority by the SyS analysts within their agencies continues to limit sharing. One mini-project was chartered to improve the ability of SyS program managers to properly communicate syndromic surveillance, the BioSense Platform, and the value of shared data to their leadership. Interestingly, several jurisdictions felt that this message would be better received by their state leadership if it came from the CDC (either informatively through targeted webinars or as a directive through restrictive funding). The output from the Leadership Communication Toolkit project team should be widely disseminated through CSTE



networks with outside assistance for SyS programs that lack the agency to advocate within their own jurisdictions.

There is also a lack of concrete skills in utilizing the tools on the BioSense Platform. CSTE and the CDC should consider how to continue to grow the skills of analysts using the shared tools. Participants appreciate the time to develop their skills during this workshop, however, basic ESSENCE skills and more advanced syndromic surveillance methodology with APIs and R is not a primary objective of the workshop. Regularly hosted interactive skills building workshops could help to continue to grow the science of syndromic surveillance and improve the skill level of state and local analysts to creatively explore the available data and relevant public health concerns in their community.

These skills are essential to capacitating the workforce to address the opioid epidemic with the available tools. The expanse of syndromic surveillance to enable real-time surveillance of emerging threats requires a highly skilled and creative workforce that can further develop surveillance products. Regional dashboards for opioid overdose surveillance can be quickly leveraged for an all-hazards approach by changing the syndrome query. As states become more comfortable with sharing data and surveillance products for opioid surveillance, they should be prepared to share additional data and interpretations for any syndrome definition.



Annex A: Agenda

CSTE Regional NSSP Syndromic Surveillance Data Sharing Workshop

Northeast HHS Regions 1, 2, 3

Facility/Location

The workshop location has been included below.

Embassy Suites by Hilton Boston at Logan Airport

207 Porter Street

Boston, MA 02128

The meeting will commence in the hotel's Mystic B Meeting Room.

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, June 11th – 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).
9:30 AM	Welcome and introductions
	Workshop kicks-off promptly with a warm-up and welcoming remarks from CSTE and
	NSSP leadership.
10:00 AM	Orientation and overview
	A review of the workshop course to orient participants toward a shared set of objectives
	and confirm expectations.
10:20 AM	Sharing activity – Part 1: Classifier evaluations
	Guided collaborations in breakout groups to evaluate four opioid crisis related
	syndrome classifiers using BioSense Platform tools. By the end of this session, each
	group will produce an evaluated classifier for use by all other groups in Part 2.
1:00 PM	Lunch break
	After each breakout group debriefs their Part 1 work, participants break for lunch and refreshment.
2:00 PM	Sharing activity – Part 2: Analytics and visualizations



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

Sharing activity – Part 3: Application and use		
Drawing from experience and breakout group discussions, we work either in breakout groups or as a full group to devise ways that insights gained from the surveillance		
products might be applied for action; e.g., prevention, interventions, or resource allocation.		
Day 1 Summary & Day 2 Preview		
Workshop facilitation team recap the accomplishments of Day 1, check-in with		
participant satisfaction, and preview Day 2.		
Adjourn		
Workshop adjourns for the day to reconvene at 9:00 AM on May 1st.		
Organized Dinner – Santarpio's Pizza		
An optional dinner for workshop participants and sponsors to socialize in a casual setting. Note that this restaurant is CASH ONLY – plan to get cash prior to departure. Please use per diem allowance for meal expenses.		

Day 2: Wednesday, June 12th – 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	Appreciate data sharing value
	Identify and document participant perceptions of the value proposition for SyS data sharing.
11:00 AM	Data sharing readiness
	Review the state of participant readiness for data sharing, and discuss solutions to overcoming barriers; e.g., legal, motivational, etc.
12:30 PM	Lunch break
	Participants break for lunch and refreshment.
1:30 PM	Action planning
	Formulate and prioritize mini-projects for participants to collaborate on post-workshop in self-organized groups.
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, June 13th.



Annex B: Data Sharing Activity Instructions

Activity - Part 1: Classifier Evaluation 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.

TASKS

- 1. Form your team.
 - a. Acquaint or reacquaint yourself with you team members. For example, have each team member share who they are, where they work, what are their agency's overall expectations of syndromic surveillance, and one thing they'd like to learn today.
 - b. Before proceeding to the next step, be sure everyone can identify what is to be accomplished.
 - c. Assign the following team roles.
 - *Operator* the person who will project their desktop and run ESSENCE or other BioSense Platform application(s) for your team
 - *Recorder* the person who will note your team's answers and findings to share with the full team
- 2. Define and note the **public health purpose** of surveillance using your assigned classifier/syndrome. Be sure to discuss 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 and note the **scope of syndromic surveillance** using the classifier on ED visit data. Be sure to address each of the following aspects:
 - 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 assigned classifier's definition and discuss anticipated results.
- Using ESSENCE or another BioSense Platform tool, examine the classifier's performance to determine how it might be refined for better performance. Consider doing the following as part the evaluation.
 - 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 performance can be improved, make the appropriate component changes, and save and share it with your team using the BioSense ESSENCE *Query Manager.*
- 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.



- 8. Prepare a 5-minute report-out to share your team's key findings with the other teams. Select or appoint a team spokesperson for the report-out and help them 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 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* the person who will share or project their desktop to run your team's shared analysis in ESSENCE or other BioSense Platform tools
 - b. *Recorder* the person who will note the team's answers and findings to share with the full team
- 2. Confirm with each team member the data they are sharing for the workshop: 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 product you'll make during this activity.
- 4. Apply the assigned classifier(s) to the shared data set and describe the results, answering the following questions:
 - a. Stratify the results by geography, age team, gender, and race (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 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. Select a team representative 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 the question(s) given the insights gained?
 - c. What were the major challenges identified that would prevent you from using the shared data or analysis?
 - d. How would you advocate to your leadership to maintain this level of shared data for the purpose of the public health response to the opioid epidemic?



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

Massachusetts Department of Public Health (Rosa Ergas) Formally prevented. See relevant document at <u>https://www.mass.gov/files/documents/2016/07/rc/mdph-confidentiality-procedures.pdf</u>.

New Hampshire (David Swenson) Informally not accepted. See Data Sharing and Use Agreement with CDC, beginning on following page.

New Jersey (Teresa Hamby) Neither expressly permitted nor barred.

New York State (Charlene Weng) Neither expressly permitted nor barred.

Pennsylvania (Kirsten Waller) Neither expressly permitted nor barred.

Rhode Island (Maria Lena Wilson) Neither expressly permitted nor barred.



Annex D: Mini-Project Charters

1. Leadership Communication Toolkit

PROJECT MEMBERS: Kristen Soto (CT), Teresa Hamby (NJ), Deborah Gould (CDC)

PURPOSE: To develop a toolkit to inform jurisdictional leadership about the value of regional data sharing for syndromic surveillance. This toolkit is intended to be used by syndromic surveillance practitioners to communicate with decision makers within their own agencies. The anticipated outcomes are to:

- 1. Inform leadership
- 2. Ask for support and guidance to implement data sharing

DELIEVERABLES:

- 1. Talking Points
 - a. Benefits
 - b. Limitations
 - c. Elements of interest for leadership/decision makers
 - i. Privacy
 - ii. Security
 - iii. Other topics as identified
 - d. The ask: Support and guidance to implement data sharing
- 2. A slide deck to demonstrate BioSense system use and functionality
 - a. Dashboards
 - b. Queries
 - c. Alerts
 - d. Visualizations
- 3. FAQs
 - a. Working document based on feedback
- 4. Project Evaluation Tool

Out of scope:

1. A CDC-hosted webinar for executive leadership

TASKS:

- a. Setup bi-weekly call to facilitate workgroup activities
- b. Utilize BaseCamp to facilitate workgroup activities and information sharing
- c. Ask for NE Regional workgroup to review this document and identify gaps
- d. Develop toolkit products
- e. Review of products by NE Regional Workgroup to solicit feedback
- f. Review of products by decision makers who are known supporters of SyS (e.g. Rachel)
- g. Finalize product based on feedback
- h. Disseminate products to workgroup
- i. Evaluate product and incorporate feedback
- j. Post "near final" product on appropriate CoP webpage for distribution to larger NSSP CoP



2. NE Region Cross-Jurisdictional Data Sharing

PROJECT MEMBERS: Veronica Fialkowski, Nomana Khan, Sarah Kimball, David Swenson, Zach Stein

PURPOSE: Define best practices in cross-jurisdictional data sharing for bordering states

DELIEVERABLES:

- 1) Special events, outbreaks, or disaster situations
 - a. Develop DUA for cross-jurisdictional data sharing for special events, outbreaks, or disaster situations
 - i. Develop use cases for cross-jurisdictional data sharing for special events, outbreaks, or disaster situations
 - b. Develop protocol for cross-jurisdictional data sharing for special events, outbreaks, or disaster situations
- 2) Routine
 - a. Develop protocol for routine sharing on residents seeking care in neighboring states

TASKS:

- 1) Special events, outbreaks, or disaster situations
 - a. Reach out NJ and PA for data sharing templates that were used during events of short duration (Pope visit)
 - b. Identify use cases and justification
 - c. Develop and test dashboard

2) Routine

- a. Explore the capabilities within the BioSense Platform to share data with states on residents seeking care in neighboring states
- b. Develop plan for routine data sharing



3. Regional Alert Network (Sys 911)

PROJECT MEMBERS : Jonah Long (PA), Shivani Arora (NYS), Veronica Fialkowski ``(VT), Mike Coletta (CDC)

PURPOSE : Identify meaningful/actionable clusters/alerts and convey that information to the LHDs/other jurisdictions in a timely and effective manner.

DELIEVERABLES :

- Identify perimeters that define a meaningful alert.
- Get familiar with Essence functionality to use "my alert" feature.
- Stakeholder feedback; Room for improvement.

TASKS :

- Mike will share resources that explain how alerting works in Essence
- Make it a practice to use Essence more often
- Use Essence to create some alerts (practice)
- Determine which strata are important to alert
- Subscribe to and share alerts with each other
- Collaborate with team members/calls/meetings communication



4. Overdose-related Opioids and Stimulants – Northeast Regional Dashboard

PROJECT MEMBERS: Jenna Strathdee, Charlene Weng, Kaamna Mirchandani, & Aaron Kite-Powell

PURPOSE: To access trends and alerts by drug overdose category and site

DELIVERABLES:

- 1. Time series for all 9 regions
- 2. Age and gender demographic map
- 3. Facility map
- 4. Patient location map

TASKS

- 1. Require aggregate-level permission of Northeast sites for both facility and patient level data
- 2. Research about similar dashboards/data presentations
- 3. Conversation about building deliverables and assigning duties
- 4. Test queries explore additional topics
- 5. Compile dashboard