CSTE

COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS

NSSP DATA SHARING WORKSHOP REPORT

South and East Regions

December 2019

with support from: KAHUINA CONSULTING

Contents

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

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Executive Summary

The initial data sharing workshop of four planned workshops engaged diverse participation from the syndromic surveillance community in the southeastern region of the country with representation from HHS Regions 3, 4, & 6. 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.

In general, participants were enthusiastic about the potential to share data through the BioSense Platform with improved functionality that allows site administrators to customize their data sharing rules. Several opportunities for continued improvement manifested in the mini-projects chartered at the end of the workshop. These include a common understanding of site metadata, training and support for new users, and defined scopes for shared data activities. The mini-projects all requested administrative and logistical support to stay on schedule. Continued support through CSTE will help the mini-projects achieve their deliverables and provide valuable insight for the continued development of the NSSP community of practice and the BioSense Platform.

Background

The National Syndromic Surveillance Program (NSSP) continues to expand with newly onboarded sites, administrators, and users with a diverse skill set and familiarity with syndromic surveillance practice and the community of local, state, and national users. CSTE, through funding from the CDC, has scheduled four data sharing workshops to expand on previous work to improve sharing of syndromic surveillance data through the BioSense Platform. The workshops are divided by geography to bring neighboring jurisdictions together to realize the value of sharing data across jurisdictional boundaries through practical activities and to build trust with other BioSense Platform users to foster continued sharing post-workshop.

Advances in the functionality of the shared tools on the BioSense Platform have improved the ability of site administrators to share data more specifically with other users on the system. The technical functionality through the AMC site administrator tool on the BioSense 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 previous challenges to routine data sharing and set a new baseline for the current workshops.

Continued efforts to prevent and respond to the ongoing opioid epidemic have benefited from frequent data submitted by state agencies to the CDC. Additional funding is being provided to states to combat opioid related injuries through increased surveillance under the Enhanced State Opioid Overdose Surveillance (ESOOS) grants. Information provided by syndromic surveillance systems has proven to be a critical component of the response. The opioid epidemic response provided the basis of the use case explored in the workshop.

The workshops are utilizing the national overdose classifier definitions developed by CDC with significant syndromic surveillance community input. These standard classifiers have allowed the workshop to focus on the value of data sharing by using a shared query definition on shared data in a shared tool environment.

CSTE contracted with Kahuina Consulting, LLC to design and deliver the workshops in consultation with CSTE, CDC, and the workshop participants to craft customized workshops for each geographic region. Kahuina's facilitation methodology is based on a model that utilizes a non-formal education (NFE) approach,[1] 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.

Workshop Description

This regional workshop brought state and local jurisdictions together from HHS Regions 3, 4 and 6 in three distinct forums: pre-workshop design calls, the facilitated workshop, and a post-workshop follow-up call. The initial design calls allowed the participants to begin to form connections with the other participants and drive the agenda of the workshop based on their needs and ability. A pre-call assessment was delivered to gauge current self-identified experience with syndromic surveillance

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

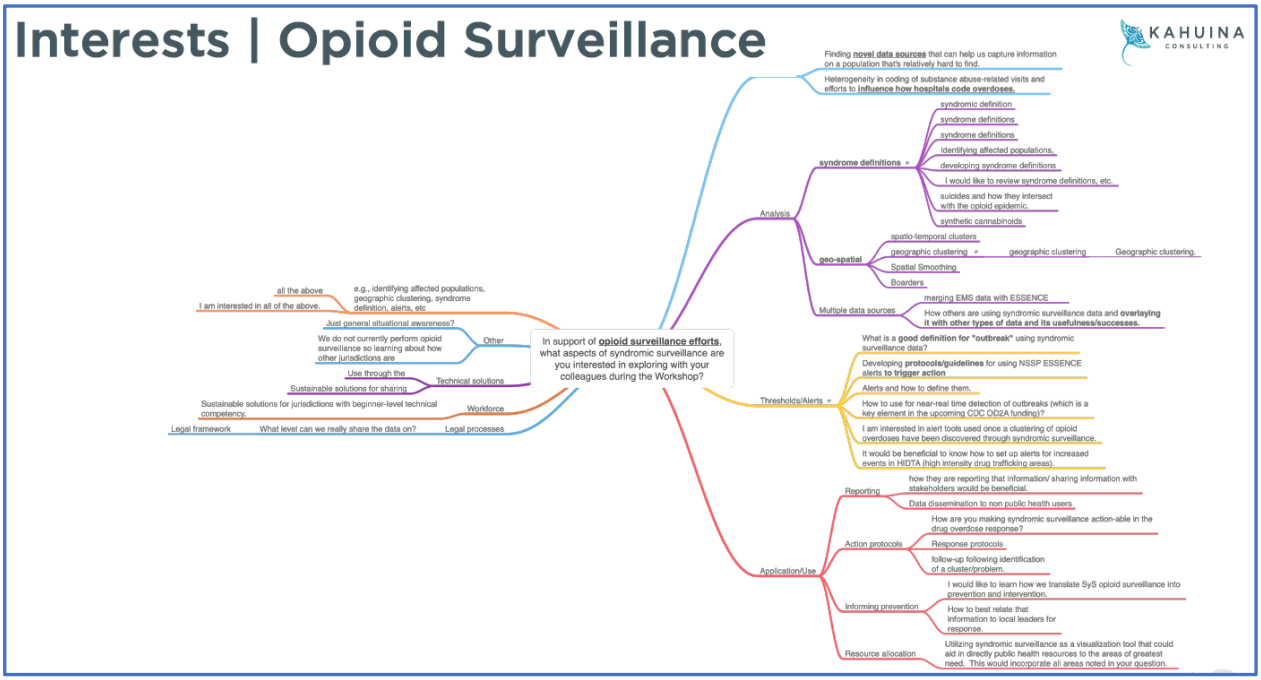
methodologies, system functionality, and current sharing with CDC programs and other jurisdictions. Additionally, the pre-workshop assessment asked for the participants to share their expectations for the workshop and what areas they wanted to explore related to shared data and the intersection with the opioid epidemic.

A total of 29 people from 17 jurisdictions participated in the workshop. They represented over 230 years of combined public health experience with almost half (44%) identifying as syndromic surveillance beginners. The participants described their goals for the workshop to include:

- Strengthened relationships with colleagues;
- Understanding of best practices 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 the timely use of surveillance data to support the CDC's and states' Overdose Prevention in States (OPIS) efforts, participants were asked to identify which aspects of syndromic surveillance they were interested in exploring with their colleagues. Figure 1 illustrates the specific interests the participants provided for opioid surveillance. These interests were categorized with analysis, alert thresholds, and application/use of the surveillance as the main groupings.

Figure 1. Opioid Surveillance Interest



Kahuina used these groupings to design the data sharing activities delivered during the in-person workshop to build the foundational value of shared surveillance amongst regional colleagues. The activities are described below and were presented to the participants during the second design call. A significant portion of the second design call was dedicated to the practicalities of sharing data through the AMC portal of the BioSense Platform. A user group was established by the NSSP to allow all

participating sites to share data with the group for the purposes of the workshop. This was expected to be done prior to the Day 1 of the workshop.

The in-person workshop was 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 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 drug-related injury surveillance and the functionality of the BioSense Platform ESSENCE application. Participants were divided into four groups (between seven and eight 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 group was assigned a syndrome classifier to evaluate using the CCQV data set in BioSense ESSENCE to answer evaluative questions based on community-defined guidance. The four classifiers explored were the CDC-developed All Drug Overdose, Heroin, Opioid, and Suicide classifier definitions. The groups then evaluated the information being returned through the CCQV data set and applied the classifiers to the 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 functionality of the BioSense ESSENCE to review the de-identified CCQV data, and experiencing how to run Chief Complaint and Discharge Diagnosis defined queries.

Each group 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.

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. 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 those products with other BioSense ESSENCE users. During their report out, the groups were asked to consider how this data could be used to inform the prevention and response to the Opioid epidemic.

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 benefited.. 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 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 brought together by the workshop, the relationships that began to develop in the small breakout groups, and the expertise demonstrated by each other. Participants appreciated the common values shared by their colleagues and the technical ability to share data through the common BioSense Platform with no mention of data sharing barriers.

Question 2 provided participants the opportunity to explore the potential that data sharing has to their work and their population's health. This was expressed in the desire to collaborate more on cross-jurisdictional projects to improve syndromic surveillance practice. This would lead to more leadership

buy-in as well as a better understanding of how to utilize shared syndromic surveillance to inform policy and strategic direction.

Question 3 elicited two major categories to additionally explore to ensure that sites will continue to share data: leadership and legal. Both of these categories relate to some form of permission that site administrators look for before sharing.

The figure below illustrates current data sharing (as reported by the participants) related to CDC and other jurisdictions. As shown, most sites are already sharing both aggregate and line-level data with CDC programs – additionally, most are either ready or willing to share with other sites. To note, Oklahoma City has yet to onboard, hence the "Unable" label applied to their sharing ability.

Figure 3. Self-reported data sharing categorization

Self-Reported Data Sharing Pre-Workshop

	Sharing With CDC Programs		Sharing With Another Site	
	Line Level	**Aggregate**	**Line Level**	**Aggregate**
AL	Active	Active	Unk	Ready
AR	Active	Active	Ready	Ready
DC	Active	Active	Ready	Ready
FL	Unk	Unk	Unk	Unk
GA	Active	Active	Willing	Willing
KY	Active	Active	Willing	Ready
MD	Active	Active	Unk	Unk
MS	Active	Active	Active	Active
NC	Active	Active	Willing	Ready
OKC*	Unable	Unable	Unable	Unable
SC	Active	Active	Unk	Ready
TN	Active	Active	Ready	Ready
Tulsa	Unk	Unk	Unk	Unk
Tarrant	Active	Active	Willing	Willing
Texas 6/5	Active	Active	Willing	Willing
TX	Active	Active	Unk	Unk
VA	Ready	Active	Ready	Ready
WV	Active	Active	Willing	Willing

*Not yet onboarded

Participants were asked to submit the legal wording that either allows or restricts their ability to share data with CDC or other public health agencies (Annex C). The ambiguity of how syndromic surveillance analysts interpret that language is echoed by their identified need for explicit leadership direction allowing or permitting syndromic surveillance data sharing. Sharing around a particular use case, like the opioid epidemic, could provide the tangible evidence needed to drive that leadership buy-in. Support from member-led organizations, like CSTE, could provide the appropriate medium to securing broad consensus to allowing site to site data sharing.

Project Initiation

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

1. Project Help! - Identify and catalogue resources for new SyS analysts and BioSense Platform users.
2. Clusters Without Borders - Establish cross border situational awareness of public health events to inform coordinated responses.
3. Interstate Data Quality Reports - Develop requirements and specifications for data quality analytics in BioSense ESSENCE.
4. Regional Overdose Dashboard - Develop a shared regional dashboard in BioSense ESSENCE for 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. The project deliverables encourage strong participation of a dynamic user base (Project Help!), building trust in the shared data (Data Quality Reports), and providing tangible use cases for continuing to share data for a public health purpose (Regional Overdose Dashboard and Clusters without Borders).

Conclusion

The SE Regional Workshop provided a valued 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. These relationships enabled rapid chartering of the mini-projects with defined deliverables for further work.

Specific to overdose surveillance, shared surveillance around state borders could prove a promising strategy to evaluate states' data to highlight changes in emergency department visits for opioid related overdoses. For example, the Clusters without Borders mini-project focused on identifying clusters of overdose related visits regardless of state boundaries can provide a comprehensive picture of where a state's residents are receiving emergency care for overdose related injuries. Further analysis could correlate this data with areas of increased public safety and law enforcement cooperation in the High Intensity Drug Trafficking Areas and provide evidence for mutual aid agreements across state lines to

address the fluidity of the opioid epidemic and how local, state, and federal public health resources can be coordinated for action.

All participants with data in the BioSense Platform actively shared patient and facility location with the workshop's user group during the workshop. Having a concrete use case or reason to share data with other jurisdictions may propel users to continue sharing data with each other and with specific CDC programs. Utilizing a use case model for sharing activities may encourage long-term data sharing. A potential use case could be defined as *rapid surveillance for emerging threats and national emergencies* with a need to share data with CDC CSELS. Parameters for the use case model could include identifying the end users that will analyze the data, proposed actions that will be taken from the analysis, and how that action will be communicated.

The majority of the workshop participants did not identify as decision makers. This was evident in the responses to assessments and the affinity grouping exercises. Despite the long tenure of some participants at the workshop, and even the median length of time that participants had been working at their health departments, those responsible for administering their BioSense site accounts do not exert the agency needed to decide to share data with another jurisdiction. CSTE should leverage this opportunity to work with the State Epidemiologists and other affiliated organizations to encourage data sharing via senior technical and political leadership at their state and local health departments.

Annex A: Agenda

CSTE Regional NSSP Syndromic Surveillance Data Sharing Workshop

South and East HHS Regions 3, 4, 6

Facility/Location

Please note that the workshop location has changed to the following:

Atlanta Marriott Northeast/Emory Area
(formerly Marriott Atlanta Century Center)
2000 Century Blvd NE
Atlanta, GA 30345

The meeting will commence in the hotel's **Peachtree Meeting Room**, and breakouts will be held in both the **Peachtree Meeting Room** as well as the **Dogwood 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

Preparation Tasks

- Respond to surveillance system information assessment
- Share data with workshop group using the AMC
    - See quick start guide on BaseCamp
- Provide answers to legal questions about data sharing on BaseCamp
- Review refence materials on BaseCamp
    - Syndrome classifier definitions
    - Syndrome definition guidance document

Agenda and Schedule

Day 1: Tuesday, April 30th – 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 an online syndromic surveillance skills inventory.

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.

10:15 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.

4:00 PM **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.

5:15 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.

5:30 PM **Adjourn**
Workshop adjourns for the day to reconvene at 9:00 AM on May 1st.

7:00 PM **Organized Dinner – Food Terminal**

An optional dinner for workshop participants and sponsors to socialize in a casual setting. Please arrange for own transportation and use per diem allowance for meal expenses.

Day 2: Wednesday, May 1st – 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.

10:00 AM **Data sharing readiness, barriers and solutions**

Review the state of participant readiness for data sharing, and discuss solutions to overcoming barriers; e.g., legal, motivational, etc.

11:00 AM **Action planning**

Formulate and prioritize mini-projects for participants to collaborate on post-workshop in self-organized groups.

12:15 PM **Workshop summary and conclusion**

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

1:00 PM **Conclude workshop**

Workshop ends. Participants may stay for lunch or take their lunch with them. All are asked to complete a post-workshop skills assessment no later than Thursday, May 2nd, 2019.

Annex B: Data Sharing Activity Instructions

Activity - Part 1: _____ Classifier Evaluation

In the ordered sequence, complete the tasks to evaluate your group's assigned classifier within the BioSense Platform environment and associated tools.

At the end of this activity, each participant should be able to…

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

TASKS

1. Review tasks 2 - 10. Be sure you understand what needs to be accomplished before proceeding.

2. Assign the following roles to participants within your group:
    a. *Operator* – the person who will share or project their desktop to run your group's evaluation operations in ESSENCE or other BioSense Platform tool
    b. *Recorder* – the person who will note the group's answers and findings to share with the full group

3. Discuss and define the **public health concern**: What is the concern as related to the opioid-crisis and what possible ways can it present in syndromic data?

4. Define the surveillance scope with the classifier using emergency department (ED) visit data by answering the following questions.
    a. Purpose or intention: What public health question(s) or action(s) do you intend to inform with the classifier surveillance?
    b. Sensitivity versus specificity: Which do you prioritize and why?
    c. Time frame: What time frame do you want to cover, and what time frame do your data cover?
    d. Data source: What inclusions or exclusions will you make on the data; e.g., facility types, etc.? What additional data sources would you use, and why?

5. Review the classifier's components and note what results you anticipate once its applied to the data. Components may include: Data elements (chief complaint, triage notes, diagnoses), key words or values for inclusion or exclusion.

6. Examine the classifier's performance and make component refinements to produce an evaluated classifier for use during the rest of the workshop. Consider doing the following as your group examines and refines the classifier:
    a. Compare and contrast results when the classifier runs against the CCQV and the workshop dataset.
    b. Visualize results in a time-series
    c. Manually review record-level data and note how records are categorized in different classifiers.
    d. Roughly assess the percentage of probable records captured by each keyword (identify which key words drive the results)
    e. Should the classifier be altered at all to improve performance of the query?

7. Discuss whether the classifier should be used at each of the following geographic levels: local, state, regional, national.

8. Share your evaluated classifier using the BioSense ESSENCE *Query Manager* with your team members.

9. Prepare to report out key findings to the group (5-minute report out) with answers to the following questions and selecting or appointing a participant to be your spokesperson during the debrief/report out.
    a. What is your group's definition of the public health concern, and how does that relate to the classifier's surveillance scope and purpose?
    b. Why did your group change or not change the classifier? If it was changed, how does it differ from where you started?
    c. What caveats or other descriptors that should accompany this classifier to help with the interpretation of results?

Activity 2: Classifier Analysis and Visualization

In the ordered sequence, complete the tasks to create surveillance products using the BioSense Platform environment and the classifier you evaluated in Activity 1.

At 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

1. Review tasks 2 - 8. Be sure you understand what needs to be accomplished before proceeding.

2. Assign the following roles to participants within your group:
    c. *Operator* – the person who will share or project their desktop to run your group's shared analysis in ESSENCE or other BioSense Platform tools
    d. *Recorder* – the person who will note the group's answers and findings to share with the full group

3. What question(s) do you want to answer, and for whom, with the surveillance product you'll make during this activity?

4. Decide if you will add any additional classifiers to your surveillance. Why were any additional classifiers selected*?*

5. Apply the chosen classifier(s) to the shared data set and describe the results, answering the following questions:
    a. Stratify the results by geography, age group, gender, and race (if available). What segment of the population is most affected?
    b. What level of data granularity is sufficient to describe the population?
    c. What additional data or information would you like to further explain your surveillance?

6. Create a time series and geospatial dashboard that can be used to satisfactorily describe the health trends in the population identified in task 4 (above) and 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?

7. Create a myAlert in BioSense ESSENCE based on your surveillance and share with all workshop attendees, consider the following:
    a. What alert thresholds were chosen related to the intent of the surveillance?

8. Discuss the interpretation of your analysis with the group and consider the following additional points:
    a. Use the list of HIDTA counties to evaluate if there is a correlation between increased classifier visits and HIDTA-designated counties.
    b. Are there any data quality, including representativeness and completeness of the data, that affect your interpretation?
    c. Do you feel comfortable with your peers using this analysis to make decisions at their health department?
    d. Develop at least three executive-level (state epi or higher) talking points that conclude the surveillance.

9. Prepare to report out key findings to the group (5-minute report out) with answers to the following questions and by selecting or appointing a participant to be your spokesperson during the report out:
    a. What question(s) and for whom is your product designed to answer?
    b. Which classifier(s) did you choose to investigate and why?
    c. What is your answer to the question(s) given the insights gained? How would you adapt your talking points for an executive-level audience?
    d. What were the major challenges identified that would prevent you from using the shared data or analysis?

Annex C: Collected Legal Language

Responses to legal questions about data sharing

QUESTIONS POSED

In anticipation of questions and requests regarding the legal-issues with data sharing, please reply to the following:

1. Is your inter-jurisdictional sharing permitted or barred under a formal agreement (e.g., a law (e.g., HIPAA) or public health authority) or informal agreement ("handshake", MOU, information sharing, etc.)?
2. If 'yes' to #1, please provide copy or hyper-link to the relevant legal agreements (templates), laws, rules, or other (either permissive or preventing)
3. For your agency, on whose authority can inter-jurisdictional data sharing be granted for…
    a. Health agency to health agency
    b. Health agency to other governmental agency; e.g., public safety

RESPONSES

Florida Department of Health (David Atrubin)

1. Inter-jurisdictional sharing of de-identified data (e.g., from state to state) is neither expressly permitted or barred in Florida. For us to routinely share data with other states or municipalities, additional discussion would need to occur within the FDOH. Here is our MOU (or a part of it) below. The collection of SyS data in FL falls under epidemiologic investigation.

RECITALS

I. Department has the duty to assess the public health status and needs of the state through statewide data collection. §381.0011(1), F.S.

II. Department's Bureau of Epidemiology is instituting a statewide epidemiological investigation of syndromes amongst emergency room patients to identify and monitor disease outbreaks in the community.

III. This epidemiological investigation will enable earlier identification of natural and manmade outbreaks of diseases of public health significance thereby triggering much earlier detection for the Department's diagnosis based surveillance system. §381.0031, F.S.

IV. HIPAA does not govern Department epidemiological investigation. 45 CFR §160.203(c).

V. HIPAA does not require a Hospital to have an authorization or offer an opportunity to agree or object before disclosing protected health information as part of Department's epidemiological investigations. 45 CFR §164.512(b)(1)(i).

VI. Hospital is a facility licensed under chapter 395, Florida Statutes.

VII. Department has the authority to examine patient records in any licensed facility for purposes of epidemiological investigation. §395.3025(5), F.S.

VIII. Information gathered from such patient records is confidential and exempt from disclosure under Florida's public records laws and may not be further disclosed to non-Department personnel in a manner that reveals the patient's identity. §395.3025(7)(a), F.S.

IX. Department acknowledges that an epidemiological investigation of this scope cannot be done in an unobtrusive manner with Department personnel at Hospital.

Here is the section of Florida's reportable disease code that, I believe, most closely applies to the sharing of SyS data. What is clear to me is that the language was written for data that are not SyS in nature. An update would be beneficial.

64D-3.036 Notifiable Disease Case Report Content is Confidential.

All information contained in laboratory reports, notifiable disease or condition case reports and in related epidemiological investigatory notes is confidential as provided in Section 381.0031(6), F.S., and will only be released as determined as necessary by the State Health Officer or designee for the protection of the public's health due to the highly infectious nature of the disease, the potential for further outbreaks, and/or the inability to identify or locate specific persons in contact with the cases.

Rulemaking Authority 381.0011, 381.003(2), 381.0031(8), 384.33, 392.66 FS. Law Implemented 381.0011(3), 381.003(1), 381.0031(2), (6), (7), 384.25, 392.53 FS. History–New 11-20-06.

Houston Health Department, Texas (Tolu Olumuyiwa)

1. For our region, sharing is permitted through a charter with the members of the Syndromic Surveillance Consortium of Southeast Texas (see next page).

North Carolina Division of Public Health (Zach Faigen)

1. NC is allowed to share data with CDC according to our mandate that allows for the collection of the ED data. I believe legally this is referring to the raw line level data, not sharing aggregate data or reports etc. Our mandate is attached.

§ 130A-480. Emergency department data reporting.

(a) For the purpose of ensuring the protection of the public health, the State Health Director shall develop a syndromic surveillance program for hospital emergency departments in order to detect and investigate public health threats that may result from (i) a terrorist incident using nuclear, biological, or chemical agents or (ii) an epidemic or infectious, communicable, or other disease. The State Health Director shall specify the data to be reported by hospitals pursuant to this program, subject to the following:

(1) Each hospital shall submit electronically available emergency department data as specified by rule by the Commission. The Commission, in consultation with hospitals, shall establish by rule a schedule for the implementation of full electronic reporting capability of all data elements by all hospitals. The schedule shall take into consideration the number of data elements already reported by the hospital, the hospital's capacity to electronically maintain the remaining elements, available funding, and other relevant factors.

(2) None of the following data for patients or their relatives, employers, or household members may be collected by the State Health Director: names; postal or street address information, other than town or city, county, state, and the first five digits of the zip code; geocode information; telephone numbers; fax numbers; electronic mail addresses; social security numbers; health plan beneficiary numbers; account numbers; certificate or license numbers; vehicle identifiers and serial numbers, including license plate numbers; device identifiers and serial numbers; web universal resource locators (URLs); Internet protocol (IP) address numbers; biometric identifiers, including finger and voice prints; and full face photographic images and any comparable images.

(b) The following are not public records under Chapter 132 of the General Statutes and are privileged and confidential:

(1) Data reported to the State Health Director pursuant to this section.

(2) Data collected or maintained by any entity with whom the State Health Director contracts for the reporting, collection, or analysis of data pursuant to this section.

The State Health Director shall maintain the confidentiality of the data reported pursuant to this section and shall ensure that adequate measures are taken to provide system security for all data and information. The State Health Director may share data with local health departments and the Centers for Disease Control and Prevention (CDC) for public health purposes. Local health departments are bound by the confidentiality provisions of this section. The Department shall enter into an agreement with the CDC to ensure that the CDC complies with the confidentiality provisions of this section. The State Health Director shall not allow information that it receives pursuant to this section to be used for commercial purposes and shall not release data except as authorized by other provisions of law.

(c) A person is immune from liability for actions arising from the required submission of data under this Article.

(d) For purposes of this section, "hospital" means a hospital, as defined in G.S. 131E-214.1(3), that operates an emergency room on a 24-hour basis. The term does not include a psychiatric hospital that operates an emergency room.

(e) Administrative emergency department data shall be reported by hospitals under Article 11A of Chapter 131E of the General Statutes. (2004-124, s. 10.34(b); 2006-264, s. 64(a); 2007-8, s. 1.)

Tennessee Department of Health (Caleb Wiedeman)

1. Well... maybe? All potentially relevant documentation is below.

TCA 1200-14-01-.15 "General Measures for the Effective control of Reportable Diseases".

1200-14-01-.15 GENERAL MEASURES FOR THE EFFECTIVE CONTROL OF REPORTABLE DISEASES.

(1) The local health officer or the Commissioner or a designated representative of the Commissioner, upon receiving a report of a reportable disease or of a suspected epidemic of disease or of a suspected case of a disease of public health significance or event, shall:

(a) Confer with the physician, laboratory, hospital, or person making the report;

(Rule 1200-14-01-.15, continued)

(b) Collect such specimens for laboratory examination as may be necessary to confirm the diagnosis of the disease and/or to find the source of the infection or the epidemic;

(c) Obtain all names and information necessary to identify and contact all persons potentially exposed to the source of the disease outbreak as needed to protect the public health;

(d) Make a complete epidemiological investigation to include (but not limited to): review of appropriate medical and laboratory records of affected persons and controls, interviews of affected persons and controls, and recording of the findings on a communicable disease field record; and

(e) Establish appropriate control measures which may include examination, treatment, isolation, quarantine, exclusion, disinfection, immunization, disease surveillance, closure of establishment, education, and other measures considered appropriate by medical experts for the protection of the public's health.

Authority: *T.C.A. §§ 4-5-202, 68-1-103, 68-1-104, 68-1-201, 68-5-101, and 68-5-104.* ***Administrative History:*** *Original rule certified June 7, 1974. Repeal and new rule filed March 31, 1977; effective May 2, 1977. Amendment filed April 20, 1987; effective June 4, 1987. Amendment filed March 30, 2004; effective July 29, 2004. Emergency rule filed October 8, 2009; effective through April 6, 2010. Amendment filed December 29, 2009; effective March 29, 2010.*

The TCA for confidentiality is below:

1200-14-01-.17 CONFIDENTIALITY.

All individually identifiable health information collected, created, and/or prepared by the Department is deemed confidential and shall not be considered a public record. The Department may disclose such information to those entities or persons as are necessary to carry out the purposes of these Rules and 1200-14-04-.01 et seq. or as otherwise authorized or required by law.

Authority: *T.C.A. §§ 4-5-202, 68-1-103, 68-1-104, 68-1-201, and 68-5-104.* ***Administrative History:*** *Original rule certified June 7, 1974. Repeal and new rule filed March 31, 1977; effective May 2, 1977. Repeal filed January 11, 1994; effective March 27, 1994. New rule filed March 30, 2004; effective July 29, 2004.*

And our trading partner agreements highlight that the data we receive will be used for "public health business practice".

TDH's general public data release policy is below (although it is currently being revised):

HEALTH DATA RELEASE POLICY
RELEASE OF AGGREGATED DATA

The Tennessee Department of Health has the responsibility to protect the confidentiality and privacy of the citizens while also adequately presenting information and data concerning conditions that affect public health. With regard to these two responsibilities, the following guidelines should be followed when presenting data for public consumption including publications or public web sites:

Rates

(1) Any rate may be presented if the population at risk is at least 100 persons. If the population is less than 100, the rate may be presented in certain circumstances as noted in the Exceptions section below. If all Exception criteria are not met, the rate will be suppressed (replaced with an asterisk or similar symbol) and a footnote added to the page indicating "rate not calculated due to population less than 100".

Numbers

1. Counts for the state, region and county totals can be shown irrespective of the number of events or population size.
2. Counts for state, region and county totals, by sex, can be shown irrespective of the number of events or population size.
3. Counts for state, region and county totals, by race, can be presented if the number of persons in each race group being presented is a least 50.
4. Counts for state, region and county totals, by race and sex, can be presented if the number of persons in each race-sex category presented is at least 50.
5. Counts for the state, region and county totals, by age group can be presented if the number of persons in each age group presented is at least 50.

Exceptions

1. If the Rates criteria are not satisfied, rates may be presented only if both of the following conditions are met:
   a) Appropriate confidence intervals are presented with all rates.
   b) Table cell subtracted from the number of total events in the same data file for the same characteristic is at least 10 ("Numerator and Denominator Rule").
2. If the Numbers criteria are not satisfied, counts may be presented only if the following condition is met:
   a) Table cell subtracted from the number of total events in the same data file for the same characteristic is at least 10 ("Numerator and Denominator Rule").

It is understood that a program within the Department of Health may adopt more strict (conservative) guidelines for data presentation. In addition, specific situations related to a public health threat could dictate more detailed data presentation, at the direction of the Commissioner of the Department of Health.

Some of our (informal) trading partner agreements have specific amendments that our partner organizations required and the contents of these varies.

3.a. Health agency to health agency for public health use cases would be okay if the public health authority is legally authorized to collect or receive the information for the purpose of preventing or controlling disease, injury, or disability.

3.b. Health agency to other government agency would probably require legal review or IRB approval if it involved PHI (any line level information). Otherwise, it would be subject to our public data release guidance.

Annex D: Mini-Project Charters

1. Project Help!

Members:

Deborah Gould (CDC)

Carly Babcock (Maryland)

Jessica Rice (Tulsa)

Madison Thomas (Tulsa)

Tolulope Olumuyiwa (Houston)

Deliverable: To build a roadmap for those new to Syndromic surveillance, on how to navigate the field and the resources available.

Purpose of the group: To build capacity across jurisdictions through support and resources for individuals working in syndromic surveillance.

Tasks:

- Assess available resources to get a sense of any gaps
- Update existing resources
    - Streamline 'quick tutorials'
    - Build up the 'tips' section of the NSSP newsletter
    - Sign up new SyS peers to NSSP CoP
    - Put together a FAQs document
- Improve organization of resources
    - House in centralized place like the new NSSP CoP website
- Re-ignite the peer mentoring program/discussions

2. Interstate Data Quality Report

Members:

Steve Maley	Stephen.N.Maley@wv.gov
Michael Thomas	Michael.Thomas@dph.ga.gov
MisChele Vickers	MisChele.Vickers@adph.state.al.us

1. What is the group's deliverable?

A page in ESSENCE that summarizes data quality and meta data relevant to data sharing between sites. The page would include number of reporting facilities, average number of visits per day, average completeness of chief complaint, average completeness of discharge diagnosis, and statistics on other variables as desired.

2. Purpose or Importance?

Different states and other jurisdictions differ greatly in facility coverage and data completeness. Foregrounding these differences removes uncertainty, a possible barrier to collaboration and data sharing between sites.

3. Tasks

1. Become savvy at using RStudio in the AMC.
2. Write R code to calculate the few key statistics mentioned above.
3. Run code for several sites and discuss the results. Modify code as appropriate. Discuss additional statistics and variables to add.
4. Talk to CDC and Johns Hopkins designers about incorporating code/page into ESSENCE.

3. Regional Overdose Dashboard

What is the group's deliverable?

Shareable regional overdose dashboard in NSSP ESSENCE

Purpose / Importance

Regional situational awareness

Standardization of what each jurisdiction is looking at in terms of overdose surveillance

3-4 Tasks

Identify project lead

Schedule meeting to flesh out dashboard contents and discuss overall schedule / meeting frequency

Have meeting to flesh out version 1 of dashboard, e.g., which classifiers, etc.

Create textbox with caveats on the dashboard

Assumptions and limitations for each contributing jurisdiction are well stated

Code of conduct expectations describing how the dashboard should be used

4. Clusters without Borders

Purpose: To establish cross border situational awareness of public health events to inform a coordinated response

Deliverable:

1. Methodology (best practice) framework that will support data sharing in BioSense platform for detection and monitoring across jurisdictional borders
2. Response protocol upon identification of clustering among jurisdictional borders

Tasks:

1. Assign project lead(s) – chairs or co-chairs (Erin Austin, Caleb Wiedeman, GA rep TBD)
2. Develop a list of projects/use cases
3. Categorize projects as temporary vs. permanent data sharing
4. Level of data sharing desired by each jurisdiction (with current AMC/ESSENCE capability and desire if not possible yet)
5. Identify legal requirements for data sharing in BioSense platform AMC and ESSENCE
6. Identify technical requirements (includes) for data sharing in BioSense platform AMC and ESSENCE
    a. Develop AMC access rules and groups
    b. List of requested enhancements
7. Identify trainings requirements for data sharing in BioSense platform AMC and ESSENCE
8. Develop shared approach for data analysis and cluster detection (queries, myESSENCE, etc.)
9. Finalize framework document

Use Cases:

1. Overdoses – permanent
2. Vaccine Preventable Diseases (hepatitis A, measles) – permanent
3. Mass gatherings – temporary
4. Natural disasters (hurricanes) – temporary