



# CSTE

COUNCIL OF STATE AND  
TERRITORIAL EPIDEMIOLOGISTS

## NSSP DATA SHARING WORKSHOP REPORT

Midwest Region

December 2019

*with support from:*



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## Executive Summary

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The final regional workshop of four data sharing workshops convened 21 representatives from 11 state and local jurisdictions across HHS Regions 5 & 7. 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 Midwest cohort maintains a Region 5 data sharing group established during the initial NSSP data sharing workshops in 2015. The Region 7 sites that participated also have long institutional relationships working to share data. The jurisdictions represented at the Midwest workshop include sites that rely on BioSense ESSENCE as their primary syndromic surveillance system, sites that are ESSENCE users but not routinely users of the BioSense ESSENCE systems, and sites that utilize vendor systems. Minnesota is in the planning process to implement syndromic surveillance. The workshop concluded with four mini-projects focused on tangible short-term outputs, with two regional projects (sharing syndromic suicide data and a Region 7 shared DUA), a data quality group, and a communications project.

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 a public health agency when an alert of increased drug and/or opioid related overdoses is observed.

Both HHS regions represented at this workshop have strong inter-agency relationships and highly technical syndromic surveillance practitioners. The sites, with support from NSSP, need to continue to ensure data parity between their jurisdictional systems and BioSense to realize the full value of utilizing shared data on a shared system. There is a strong willingness and readiness to share data from most sites. However, there are continued legal issues in Region 7 that require a shared DUA, data sources in Region 5 that may impact interpretation, and still some state-specific issues that linger. Utilizing the opioid epidemic and associated syndromes as an initial use case to implement syndromic surveillance data sharing 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.

## Background

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The Midwest workshop was the last in a series of NSSP regional data sharing workshops. The objectives, design, and delivery are consistent across the four national workshops. The Midwest workshop followed a similar design to the West workshop with extended time available to charter the mini-projects. There is extensive BioSense platform and data sharing experience in the Midwest region; the first NSSP data sharing workshop was held in Region 5 in 2013 and the region convenes a regular data sharing call. The workshop also benefited from the experience of Region 7 users and the explicit need for sharing between Kansas, Missouri, and Nebraska.

The activities 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 four syndrome classifier definitions developed by the CDC with syndromic surveillance community input (All Drug, Heroin, Opioid, 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

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This regional workshop engaged state and local jurisdictions from HHS Regions 5 and 7 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 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.

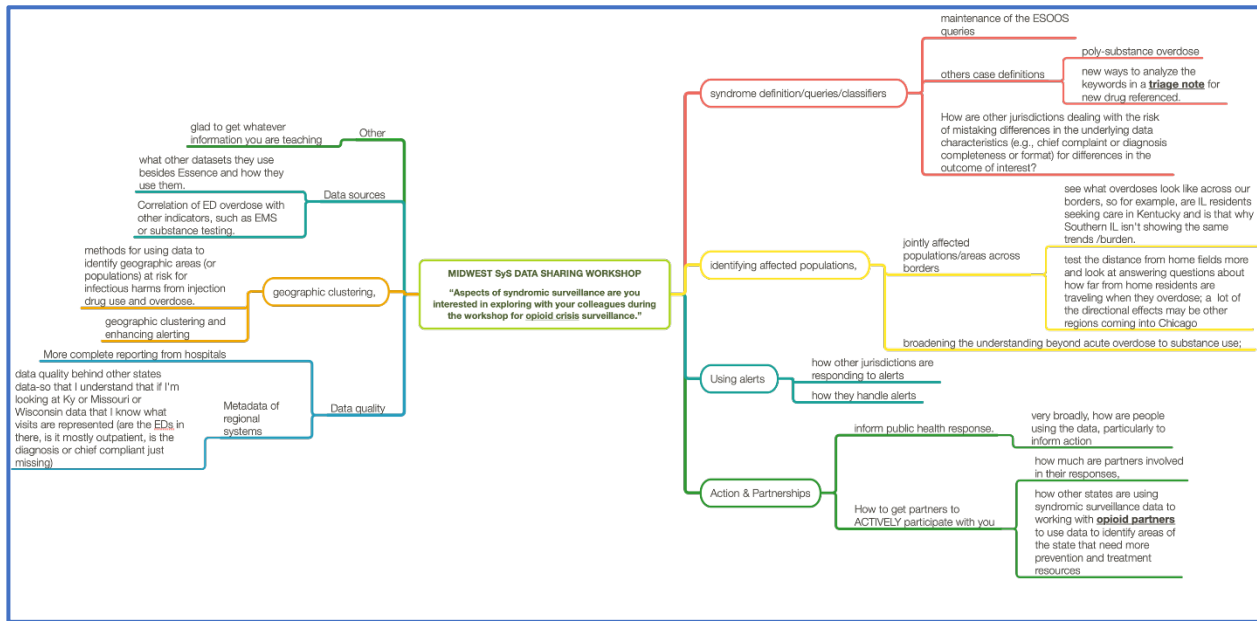
This workshop had 21 participants from nine states and two local public health agencies. They represented over 175 years of combined public health experience and more than 40% of respondents reported being experienced or highly experienced using BioSense ESSENCE. The participants described their goals 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.

There are very strong ESSENCE users in the Midwest region. All of the jurisdictions (with the exception of Minnesota) submit data to NSSP's BioSense Platform, but few utilize the BioSense ESSENCE tool for routine surveillance; some sites actually have a degrading feed where fewer sites are now submitting under BioSense than submit to their own internal system (e.g. Indiana).

Figure 1 illustrates the specific interests the participants provided for opioid surveillance. These interests were categorized around building active partnerships, defining syndromes, and using alerts to understand the epidemiological profile of affected populations. The Midwest regional workshop participants had a strong analytical perspective for opioid-related surveillance and currently use, or are considering use of, syndromic surveillance to respond to the Opioid Epidemic – syndromic surveillance data is utilized to not only respond to acute opioid overdoses but also to identify populations and geographic clustering for development of prevention and harm reduction strategies with hopes of preventing ED visits for opioid overdose (in addition to infectious disease prevention from injection drug using behavior.)

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. This was the first workshop where all BioSense-participating sites did not share data (i.e., Missouri and Nebraska did not share data during the workshop). Missouri was waiting for approval that was not received, and Nebraska was insistent on having an executed DUA. The remaining sites all shared aggregated data classified on both patient and facility location. Minnesota is not an active BioSense participant and, therefore, did not share any data.

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 four groups of five with a mix of experienced and novice syndromic surveillance and ESSENCE 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 four classifiers explored were the CDC-developed All Drug Overdose, Heroin, Opioid, and Suicide 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 – however, this cohort of participants were overall very analytical with strong epidemiological skills.

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 this type of 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 identifying a use of this surveillance for case identification and follow-up as well as evaluating the effectiveness of public health interventions. For example, the team that evaluated the Suicide classifier was interested in further evaluating triage notes to understand the more nuanced reasons for a visit being classified as suicide-related. This team also had some concern with the definition and noted a need for more specificity between attempted suicide and self-harm not related to suicide.

The other teams began to identify the reliance on discharge diagnosis for classification. They began to explore additional functionality in ESSENCE to identify the top chief complaint words and percent of the chief complaint and discharge diagnosis with informative data (i.e. non-null and appropriately formatted ICD-10 codes). Additional exploration may lead to insight into the effect of discharge diagnosis on the trend of the classifiers or if this effect is limited to the observed volume of visits.

### *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, 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 the data sharing activities, several themes emerged regarding the utility of the available tools and data. With the exception of some nuanced revisions to the Suicide classifier, none of the teams adjusted the shared classifier definitions, reinforcing a shared trust in the syndrome definition development process (with sufficient documentation). Following a similar process should help with real-world acceptance of a new shared syndrome for an emerging threat.

The products developed and presented were primarily aimed at the analyst level. Despite comments during Activity 1 about how the data could be used by leadership and inform a wide range of audiences, the utility of the dashboards that were created during Activity 2 were limited to analysts and epidemiologists with limited discussion about the uniqueness of viewing and accessing the shared data. This could be due to the limited sharing that was available to the Region 7 group (only Kansas was actively sharing data) or that Region 5 has consistently had active conversations about sharing data (even if the mode of that sharing is not through BioSense). One team did identify how they would incorporate this data into a regional report that was already being shared on suicide following an Epi-Aid.

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. The focus of the teams was very much on the data due to the Midwest cohort's strong analytical skills. The ability to interpret the data with an understanding of the underlying data was very prominent in the displayed products. One team produced a dashboard of almost entirely data quality metrics with extremely useful approaches to quickly visualizing the completeness and usefulness of other sites' data.

The aggregated data details seemed to be sufficient for the use cases described. There was mention of further refining the public health action steps to take from a signal by looking through the line lists of visit details. The Suicide classifier, which is more case-based, may also require line-level data exploration to better determine which cases are truly suicide-related. However, the primary use case for line-level data exploration is not situational awareness or regional trend analysis – the main reason to share line-level data would be to allow states to see their residents that are seeking care in another jurisdiction. Further enhancements to the AMC interface may allow this level of control without exposing intra-state line level data to other sites.

## Affinity Grouping

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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.”

Overwhelmingly, responses centered around teamwork and sharing expert knowledge with each other to improve their skillset and understanding of BioSense's ESSENCE tool. Additionally, there were specific features and tools of BioSense ESSENCE that participants found useful, including ways to filter the data, save those filters for future use, and event-specific dashboards (e.g. the Lollapalooza Dashboard). There was also a shared consensus on the utility of a clear purpose for sharing data and communicating that purpose with each other during the exercise to better interpret and understand the limitations of the shared data's findings.

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 \_\_\_\_\_.”

The resulting categories were focused on improving the efficiency of public health surveillance and response by maturing their practice through strengthened collaboration. There were several responses related to increasing the utility of data to define and address public health issues facing their communities. The aspiration of increased specificity of a public health issue was juxtaposed with a desire to have better general situational awareness and public health preparedness.

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 are actively sharing a minimum of aggregated data through the BioSense Platform with CDC programs and other sites. Almost half report already actively sharing data with CDC programs. Minnesota is unable to share data due to a lack of participation on the BioSense Platform. However, there was limited reason given for why Indiana and Michigan are unable to share data. Michigan expressed a need for a concrete use case – however, when presented with a use case to share cross-border data for opioid surveillance and response, they still reported an inability to share data.

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
Illinois	Yes	NA	Yes	Willing	Willing	Willing	Active
Indiana	Yes	NA	Yes	Willing	Willing	Unable	Unable
Marion County, IN	Yes	NA	Yes	Willing	Willing	Willing	Willing
Linn County, IA	Yes		Yes	Unknown	Unknown	Unknown	Unknown
Kansas	Yes	NA	Yes	Active	Active	Ready	Willing
Michigan	Yes	Good will	Yes	Unable	Unable	Unable	Unable
Minnesota	Planning	Good will	Yes	Unable	Unable	Unable	Unable
Missouri	Yes	Bed # > 20, state law bed #<20, DuA Yes	Yes	Active	Active	Willing	Willing
Nebraska	Yes	NA - State Law for ED	Yes	Active	Active	Willing	Willing
Ohio	Yes	Yes	Yes	Active	Active	Unknown	Unknown
Wisconsin	Yes	Yes	Yes	Active	Active	Unknown	Ready

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

“\_\_\_\_\_ will get me fully sharing.”

The responses to this statement were grouped to form the mini-project ideas. The ideas that emerged were more nebulous than previous workshops – however, there was strong support for a communication-like project. The details for what the project would focus on were delegated to the groups to work out during their chartering exercise.

## Project Initiation

<sup>1</sup> 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.

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

1. Data Quality – Share knowledge about shared data and standard data quality metrics;
2. Suicide Data Report – Include suicide-related syndromic surveillance in the Region 5 suicide report;
3. Shared DUA – Develop a shared DUA that enables Region 7 data sharing;
4. Communications Guild – Improve communication for data sharing in the Midwest area.

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 several 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.

Data quality and the need for a shared data use agreement are similar to other workshop projects. The Shared DUA Project Team consisted of Region 7 sites (Kansas, Missouri, and Nebraska) to conclude ongoing conversations needed to share data between the three states. The group is focused on utilizing a shared DUA that incorporates the specific restrictions faced by Nebraska. Further investigation into the eHealth Exchange Data Use and Reciprocal Support Agreement (DURSA)<sup>2</sup> may help offer a solution to the need for a shared DUA held by all participating sites.

The Suicide Data Reporting Group builds on previous work done in Region 5 following an Epi Aid to investigate an increase in deaths by suicide. Data is already being shared from other sources. This project may initiate with Region 5 sites using the Suicide classifier to share aggregate data in the report (if not through the BioSense platform directly).

The Communications Guild Project is responding to a need for streamlined communications following the sunset of ISDS. There are several initiatives (including a community Slack channel) that syndromic surveillance analysts are unaware of. The output of this group should assist NSSP in improving the utility of the NSSP Community of Practice's Knowledge Repository. NSSP should also consider the continuity of syndromic surveillance technical skills and knowledge in a rapidly expanding and diversifying community.

Each group presented their refined project charter on the follow-up call. The data quality visualization project has done significant work drafting several dashboards that track various completeness statistics. They have also developed a metadata sheet to be completed and shared. The project team will need to liaise with NSSP to determine how that information is completed, accessed, and shared. Sharing data quality analytics may enable other jurisdictions to share data; the scope of the shared data is limited to completeness statistics.

The DUA template project did have some additional follow-up in collecting various state DUA language. The workshop also prompted the participating states to have conversations with their agencies' legal departments. The eHealth Exchange's DURSA was suggested as a potential solution to the shared DUA. All signatories sign one master agreement with use case specific addendum. Syndromic surveillance for events of public health significance could define a use case.

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<sup>2</sup> <https://ehealthexchange.org/onboarding/dursa/>

The Suicide mini-project is continuing conversations with the regional suicide reporting team that was formed after an Epi Aid in Ohio. At this point, the regional group is focused on mortality and is less interested in morbidity. However, it was suggested that the project continue to quantify the morbidity and compare the syndrome classifier developed in BioSense ESSENCE with the classifier developed for the Epi Aid. The project will continue to liaise with the regional suicide group to understand where they can provide value through syndromic surveillance.

There was little movement in the Communications Guild other than to identify various means of communication channels. However, this group could be beneficial in defining the requirements for communications that can be used by the incoming community of practice association.

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 to maintain energy from the workshop. Consolidation and active management of the workshop projects will assist in delivering sustained improvements in regional data sharing.

## Conclusion

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The Midwest Regional Data Sharing Workshop provided a valuable opportunity for a diverse mix of technical syndromic surveillance analysts, program managers, and data managers to convene, actively share data through the BioSense Platform, and manipulate shared analysis using the BioSense ESSENCE environment. The participants were allotted ample time to work in regional groups to advance their mini-projects. Not every jurisdiction shared data during the exercise – however, there was strong participation from sites that do not routinely utilize the ESSENCE tool of BioSense (i.e. Minnesota and Ohio). The mini-projects continue to highlight the need for standardized permissive documentation, an understanding of data quality to aid interpretation, and improvement in community and NSSP communications.

Only one of the mini-projects focuses on the use of shared data – however, the intent is to augment an existing shared report with syndromic surveillance data. This project does not utilize the shared platform – however, the shared analytics and utilization of the Suicide classifier is a step towards more sustained sharing in the system. The group may find efficiencies in establishing a shared dashboard to standardize the data submission across sites.

As identified in the other workshops, a significant skill gap remains between frequent BioSense ESSENCE users and those with local systems. NSSP may consider how to leverage their subject matter experts to actively support and manage shared data projects to minimize the skill gap. The Midwest region also experiences a degradation in the fidelity of data submitted to BioSense. Representativeness in some sites has decreased over the last several years. Concerted effort should be made to maintain parity between local systems and BioSense. Otherwise, shared data will cease to be reflective of the true depiction of the underlying healthcare-seeking population.

The DUA mini-project highlighted the need for a common DUA that is shared between participating states, rather than one-to-one DUAs. This is very similar to the DURSA model established by the eHealth Exchange. NSSP may be able to leverage these existing frameworks rather than defining a new DUA criteria. Additionally, a DUA that meets the expectations of any specific sites (in this case, Nebraska, Missouri, and Kansas), may not be acceptable to other partners.

Comfort with the technology is growing; there was general acceptance of the site-shared data and the shared classifiers used to produce the surveillance products. New ways of assessing data quality were explored as well as methods to restrict analysis to certain patient classes (e.g., avoiding the inclusion of large volumes of urgent care data from some sites).

There continues to be discordance between what is and is not legally allowed by some states. Most sites do not have formal prohibition against data sharing – however, they still claim an inability to share data. This contradiction reflects a need to elevate the conversation to decision makers with more formal guidance through the chain of command.

Communication remains key to promoting sustained data sharing on the BioSense Platform. The Midwest region is a very technically savvy group that is driven by a need to ensure the utility of the BioSense for their site-level syndromic surveillance. CSTE and NSSP should exploit this energy and need to further identify and develop use cases that improve system functionality and the application of shared data.

## Annex A: Agenda

# CSTE Regional NSSP Syndromic Surveillance Data Sharing Workshop

Midwest HHS Regions 5 & 7

## Facility/Location

### Illinois Department of Public Health

69 W Washington Street  
Chicago, IL 60602

## 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, August 6th – Discovering the Value of Data Sharing

<b>8:30 AM</b>	<b>Participant arrival and set-up</b> 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).
<b>9:00 AM</b>	<b>Welcome and introductions</b> Workshop kicks-off promptly with a warm-up and welcoming remarks from CSTE and NSSP leadership.
<b>9:30 AM</b>	<b>Orientation and overview</b> A review of the workshop course to orient participants toward a shared set of objectives and confirm expectations.
<b>10:00 AM</b>	<b>Sharing activity – Part 1: Classifier evaluations</b> 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.
<b>12:00 PM</b>	<b>Lunch break</b> After each breakout group debriefs their Part 1 work, participants break for lunch and refreshment.
<b>1:00 PM</b>	<b>Sharing activity – Part 2: Analytics, visualizations, and application or use</b>

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 colloquies.

- 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 August 7<sup>th</sup>
- 7:00 PM**      **Optional: Organized Dinner – Miller’s Pub**  
An optional dinner for workshop participants and sponsors to socialize in a casual setting.

## Day 2: Wednesday, August 7<sup>th</sup> – 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, August 8<sup>th</sup>.



## 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

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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 **public health purpose** 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**

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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

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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

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**Illinois (Stacey Hoferka)**

Permitted.

**Indiana, Marion County (Brittany Yarnell)**

Formally prevented.

Our agreement with CDC to share with the NSSP BioSense ESSENCE.

**Iowa, Linn County Public Health (Mechelle Carter)**

Permitted.

MMC and LCPH BioSense 2 DUA. Covered by Other Health Agency Uses.

4))Data Set access and use section

a) Provider acknowledges and agrees that as part of BioSense 2.0, the data set may be used and/or disclosed for the following purposes.

III)Other health agency uses (local state and federal gov health agencies. other agencies consistent ...)

(1)To facilitate the interchange of information that can be used to coordinate responses and monitory events routinely and during a potential health event.

(2)For early detection...

**Kansas (Greg Crawford)**

Neither expressly permitted nor barred.

**Michigan (Katie Arends)**

Permitted.

**Missouri (Fei Wu)**

Permitted.

See relevant document at <https://health.mo.gov/data/essence/pdf/hipaa.pdf>, included for reference beginning on following page.



**Nebraska (Sandra Gonzalez)**

Permitted.

Inter-jurisdictional sharing is permitted, however a Data Users Agreement is required.

See Nebraska's Syndromic Surveillance statute 71-552

(<https://nebraskalegislature.gov/laws/statutes.php?statute=71-552>), and Revised Statute 71-503.01

(<https://nebraskalegislature.gov/laws/statutes.php?statute=71-503.01>), included for reference beginning on following page.

**Ohio (John Hubbard)**

Informally not accepted.

**Wisconsin (Daniel Bedford)**

Neither expressly permitted nor barred.

## Annex D: Mini-Project Charters

### 1. Data Quality

#### PROJECT MEMBERS:

Brittany Yarnell (byarnell@marionhealth.org); Roger Zornes (roger.zornes@ks.gov); Jeanne Jones (Jeanne.jones@ks.gov); Aaron Kite-Powell (lyv8@cdc.gov); Michael Sheppard (oul2@cdc.gov); Jennifer Adjemian (gdn5@cdc.gov); Sarah Brister (sarah.brister@illinois.gov)

PURPOSE: To share knowledge about the data provided and offer standard data quality metrics.

#### DELIVERABLES:

- Data Quality Dashboard
- ESSENCE and R versions
- Possibly suggest myAlerts with some of the widgets
- Limitations and Key Facts Guidebook
- Metrics
- Table for priority fields with checks for who includes what

#### TASKS:

1. What should be in the one pager for the guidebooks
2. What should go into the dashboard(s)

#### AVAILABILITY/INTEREST:

Brittany Yarnell: REVIEWER OF PRODUCTS

Roger Zornes: DASHBOARD TEMPLATE

Jeanne Jones: SHELL OF GUIDEBOOK

Aaron Kite-Powell: DASHBOARD TEMPLATE

Michael Sheppard: SHELL OF GUIDEBOOK

Jennifer Adjemian: REVIEWER

Sarah Brister: REVIEWER

### 2. Syndromic surveillance inclusion in Region 5 Suicide Data Report

#### PROJECT MEMBERS

IL-Stacey Hoferka

OH-John Hubbard and Kara Manchester

WI ?

IN ?

Michigan ?

IN-Marion County

#### PURPOSE

Include morbidity data from syndromic surveillance across 5 states into a currently developing youth Region 5 suicide report for Midwest Injury Prevention Alliance (MIPA).

#### DELIVERABLES

#### TASKS

1. Invite MIPA to present to next Region 5 SyS data sharing meeting
2. Review data template for syndromic feedback
3. Share suicide syndromic developed during Stark County OH, EpiAid 2018

### 3. DUA Template Design for Region 7

#### PROJECT MEMBERS:

Fei W – Missouri

Greg Crawford – Kansas

Sandra Gonzalez- Nebraska

Stephanie Larocco, Michigan

**PURPOSE** Develop a broad scope outline of draft multi state DUA that can serve as a template of common use of Syndromic information, and limitations on types of information shared, level of detail in statistics, and prohibit subject matter areas.

#### DELIVERABLES

Template of a legal agreement, containing elements of each state's limits on data to be used, ED and Urgent cared, limits on data partners, limits on sharing to non-Public Health entities.

#### TASKS

1. Each jurisdiction to share existing DUAs 1 is good more OK
2. Bullets points on sharing of information
3. Bullets on limitations

#### 4. Midwest Regional Syndromic Surveillance Data Sharing Communication Guild

##### PROJECT MEMBERS

Susan Thomas, Missouri DOH

Michele Hoover, CDC

Michelle Carter, Linn County

Harold Gil, Indiana SDH

Kayley Dotson, Indiana SDH

Nate Write, Minnesota DPH

Katie Arends, Michigan DHHS

Kathleen Hartnett, CDC

Megan Patel, Illinois DPH

Daniel Bedford, WI DHS

Ruth Koepke, WI DHS

##### PURPOSE

Provide a/or tool(s) for regular communication for data sharing within the Midwest regions 5 & 7.

##### DELIVERABLES

- Find a platform for the group to use for communication.
- Find a platform for sharing information (may not be the same as the communication platform).
- Provide a list of individual members contact information.

#### TASKS

1. Explore the use of different platforms for communication (listserve, basecamp, slack, whatsapp).

2. Determine who is responsible for the creation and maintenance of the communication platform(s) (be it a listserve, basecamp, slack, whatsapp).
3. Determine members of the group/ develop a directory with all of the individuals and their contact information.