

Check! Explore barriers and solutions to data sharing on BioSense 2.0

Green Paper from the 2013 ISDS Conference

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Introduction

The benefits of inter-jurisdictional data sharing have been touted as a hallmark of BioSense 2.0, a cloud-based computing platform for syndromic surveillance. A key feature of the BioSense 2.0 platform is the ability to share data across jurisdictions with a standardized interface.

Jurisdictions can easily share their data with others by selecting data sharing partners from a list of participating jurisdictions. Technically the process is simple, however there are several other considerations (discussed herein) to be taken into account before and after deciding to share data with the larger BioSense community.

This green paper is a continuation of several discussions stemming from a workshop hosted by the International Society of Disease Surveillance (ISDS) in collaboration with the Association of State and Territorial Health Officials (ASTHO), with the support of the U.S. Centers for Disease Control and Prevention (CDC). This initial workshop brought together epidemiologists from city, county and state public health departments primarily located in the US Health and Human Services Region 5. The workshop documented (Appendix 1) a variety of known benefits to data sharing, including:

- Cross-border case-finding
- Identifying patterns or trends (local, state, regional, federal)
- Emergency preparedness planning and partner notification
- Estimating an end to an event, based on declining trends in neighboring areas
- Mutual aid
- Ensuring national situational awareness for federal partners
- Hypothesis generation and testing
- Retrospective analysis to improve public health practice

Members of this workshop composed an open letter to the BioSense Governance Group (Appendix 2) reporting on the top priorities and suggestions for functionality and documentation that would support data sharing among regional partners. Several members of the workshop coordinated a roundtable discussion at the ISDS 2013 annual conference (Appendix 3). The annual ISDS conference attracts members across disciplines including practical epidemiologists, statisticians, researchers, informaticians and academic scholars. The objective of the roundtable was to open the conversation to the wider surveillance community and find potential solutions to the three primary barriers to data sharing originally identified by the workshop: legal/ethical concerns; unknown quality of the shared data; and the need for more granular (user role-based) sharing.

Purpose

The purpose of this paper is to summarize the general and breakout group discussions facilitated by the roundtable members. This paper does not make any specific policy recommendations, however, we intend for the feedback captured in this document to lead to improvements in the BioSense 2.0 platform and application. The goal is to increase meaningful inter-jurisdictional data sharing by identifying existing barriers and user-generated solutions.

Roundtable

Presenters began by posing general questions to audience members regarding their use of BioSense and, subsequently, solicited ideas for additional benefits or solutions that had not been identified by the workgroup. We used an audience participation system to collect answers to the initial questions.

Questions and feedback gathered from the general discussion included:

1. Is BioSense 2.0 your primary syndromic surveillance analytic tool?
2. What other syndromic surveillance tools are used?
3. Is there agreement regarding the benefits of data sharing identified by the workgroup?
4. What barriers do the roundtable participants encounter?

The majority of participants (87%) at the roundtable did not use the BioSense 2.0 application as their primary syndromic surveillance tool. Local analytic tools continue to be prominently used, chiefly ESSENCE (aberration detection software licensed by the John Hopkins Applied Physics Lab). Additionally, a vast majority of audience members (93%) agreed with the benefits of data sharing identified by the original workgroup.

From the survey it became clear that legal concerns (such as protected health information) and the unknown quality of the shared data are the two greatest barriers to data sharing. A minority of participants noted concerns in sharing data when there is ambiguity over who can access the shared data; however having local administrators assign user roles (restricting access) may alleviate some of the legal concerns.

During a general discussion, we heard that there may be institutional rather than individual practitioner concerns with sharing data. Institution-level apprehension may be partly alleviated by sharing aggregate, rather than line-level, data. Additionally, regardless of what level of data is shared, inter-jurisdictional interpretation can be improved if contributors' interpretations are included along with the raw numbers.

Following this brief discussion, the roundtable was divided into four facilitated groups to discuss potential solutions to the data sharing barriers previously mentioned. Roundtable attendees were asked to participate in the group discussion they were most interested in.

Breakout groups

What kind of metadata do we need?

As identified in the workgroup, metadata needs to be made available to interpret shared data correctly and realize any significant use. This information should be presented through the BioSense 2.0 application where shared data is visualized and specific to the jurisdiction sharing the data. The following metrics were proposed as essential: number of hospitals in data set, percent of jurisdiction population covered by reporting hospitals, percent of facilities actively

reporting, and the percent of variables mapped to known values. Additionally, the breakout group suggested capturing the demographics of the underlying covered population and identifying which variable is being used to define syndromes (i.e. chief complaint [pick list or free text], nurse triage notes, or discharge diagnosis).

The Distribute Project (an ISDS proof of concept for syndromic surveillance and data sharing) produced a tool for collecting metadata (Appendix 4). A similar tool could be used in the BioSense 2.0 community. Further discussions are needed to identify who is responsible for maintaining jurisdictional metadata, how often it needs to be updated, and how BioSense 2.0 application users can access it. Identifying a jurisdictional data steward will also enable a community of practice to communicate the interpretation and quality of jurisdictional data.

Which data quality metrics are important?

The discussion of data quality produced generous amounts of feedback. Currently, the BioSense 2.0 provides very few metrics on the quality of the data being displayed through the analytic application. Again, the need for a data steward was reinforced. A jurisdictional data steward list should be maintained. These individuals should have knowledge of the locker data as well as the ability to grant sharing permissions, and their contact information should be accessible. The contact information would allow for more timely communication between jurisdictions and allow jurisdictions to directly request data sharing.

Jurisdictions need to agree upon and establish etiquette for data sharing. This would facilitate trust-building between jurisdictions for the purpose of sharing data. Etiquette guidelines should be prominently communicated and agreed upon when accepting shared data.

Planned changes in the database schema or coding systems need to be communicated with all persons/jurisdictions dependent on that database before they occur. Conversely, a jurisdiction should also alert the database managers when there has been a change that will affect proper mapping (i.e. adding/removing facilities, changes to facility names).

Jurisdictions should consider implementing a standardized process for assessing data quality and defining a set of data quality measure thresholds so that the data-sharing approval process at the source jurisdiction is made more systematic and rapid. Through this method, data sharing would not be hindered by ad-hoc data quality analyses at the source jurisdiction, which typically slow the data-sharing process. Similarly, developing standardized data reporting guidelines should be considered for greater consistency regarding such things as lowest level of geography for analysis, jurisdictional data caveats, and handling of out-of-state or out-of-country-data.

How can user roles and permissions be used?

In the current BioSense 2.0 application, there are two types of users: a local administrator and a local user. The administrator has access to the data lockers and the ability to grant data sharing permissions to other jurisdictions. The administrator also approves local users' access to the BioSense 2.0 application. How a jurisdiction defines a user is entirely dependent on that jurisdiction, and the group first discussed our assumptions about the type of users that might be

permitted to access data in BioSense. The group identified several types of users, in addition to health department staff, that would be interested in the data, including hospital infection prevention and IT staff, researchers, third party not-for profit organizations. Therefore, without stratified user roles, jurisdictions have limited control over access to their shared data. Permissions would be granted without certainty as to the composition of users in that jurisdiction..

The level of sensitivity of the data was also explored. With ambiguous questions facing public health departments, such as “who owns the data”, jurisdictions need to have more granular control over user roles and permissions. Public health practitioners are the data stewards responsible for hospital data. In regions with fewer facilities among the population, even county-level data must be protected, as it could easily represent proprietary data of one facility. BioSense does not currently provide the spatial granularity to limit regional data to a subset of users in which the information is most relevant.

The group also acknowledged some of their own limitation at this time as a impediment to data sharing. Nationally, several state or regional health departments have not engaged in syndromic surveillance previously, and are implementing BioSense in accordance with Meaningful Use. Under those circumstances, the prospect of sharing with other jurisdictions is a lower priority at this time. Important consideration about the legality of sharing with other jurisdictions and the need for a data use agreement between jurisdictions requires further review.

While the group was in favor of sharing for the benefit of public health, they recognized the responsibility inherent in protecting the data on behalf of the hospitals they are actively engaging in the process. Solutions that resulted from this discussion included the need for more user-specific sharing rights vs. the current jurisdictional options, hospital specific access for providers, a template DUA for inter-jurisdictional data sharing and geographic customization of the portion of data shared with specific users.

Potential solutions to our barriers?

First and foremost, we need to alleviate some of the burdens identified with data sharing. In response to metadata collection, it was suggested that a standard form be used to collect jurisdictional data. This form would ideally be filled out by the jurisdictional administrator and the collected metadata would be available through the BioSense 2.0 application. Scheduled reviews and updates of the information should be the responsibility of the jurisdiction.

Having the ability to comment on data sources, either as the jurisdictional administrator or another user may build trust in the shared data. For example, if a jurisdictional administrator knows that there is inconsistency in a data feed, the inconsistency should be communicated with all users sharing data for analysis. In addition to qualitative comments, data quality metrics should be available for all shared data sources. A standardized data quality score was suggested as a way to compare data sets and allow users to filter the shared data sets based on the acceptable level of quality required for analysis.

As discussed in the user roles and permissions breakout group, having more granular control with which type of users can view shared data will alleviate some of the ambiguity associated

with blindly sharing data with a jurisdiction. The breakout group also suggested that federal entities share data with state and local jurisdictions. The CDC has requested that all jurisdictions share data with the CDC, however, other federal government entities (such as the Departments of Defense and Veterans Affairs) do not share data with the BioSense Community. Sharing federal data sources with state and local jurisdictions may help to foster trust within the community.

A larger question that remains unanswered is the legality of sharing. Public health practitioners often lack the legal knowledge to make judgments about how data sharing is covered by the original data use agreement with contributing facilities, when these agreements need to be renegotiated, and when data is considered protected health information. A comprehensive review of local and state regulations surrounding public health data collection and sharing would benefit the BioSense 2.0 community.

Conclusions

We intend for this paper to continue the dialogue between jurisdictions participating in BioSense 2.0, BioSense 2.0 developers, and encourage the CDC to improve the data sharing process within the BioSense 2.0 application. The community is in agreement that there are definitive benefits to sharing data. The ISDS Distribute Project was a proof of concept that data can be shared with minimal effort and used for meaningful analysis. The enhanced functionality of the BioSense 2.0 and the ability to combine data feeds into common analysis requires that data sharing barriers be addressed, which will lead to greater jurisdictional participation and more accurate interpretation of the data.

Communication is a key theme to overcoming several barriers. Systems and channels need to be in place so users know who to contact and communicate their data sharing needs with. If these are not in place and well-defined, jurisdictions may encounter obstacles resulting in inefficient and ineffective data-sharing practices. For the purpose of sharing data, knowing who to share data with and how to share is as important as knowing that the quality of the data is satisfactory.

When interpreting shared data, the quality of that data is paramount. Without a standardized approach to assessing the quality and validity of the data, the interpretation becomes meaningless. Data quality measures should be available for each jurisdiction's data set. Metadata for the jurisdiction should also be easily assessable, so that epidemiologists can assess the value of adding other jurisdictional data to their analysis.

With a clear understanding of the barriers, we now have the opportunity to formulate solutions. This discussion centers not only the need for effective inter-jurisdictional data sharing but an effective community of practice collaboration. Using workshop feedback to shape future technical advances in BioSense 2.0 may result in not only more effective community cooperation, but also increased syndromic surveillance capacity.

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Appendices

1. ISDS Report¹ following HHS Region 5 Data Sharing Workshop
2. Letter to BioSense Governance Board
3. ISDS Annual Conference Roundtable Abstract
4. Distribute Metadata Collection Tool

¹ Full copy of Report and Appendices available here: <http://www.syndromic.org/resources/data-sharing>

Appendix 1: HHS Region 5 Data Sharing Workshop Report

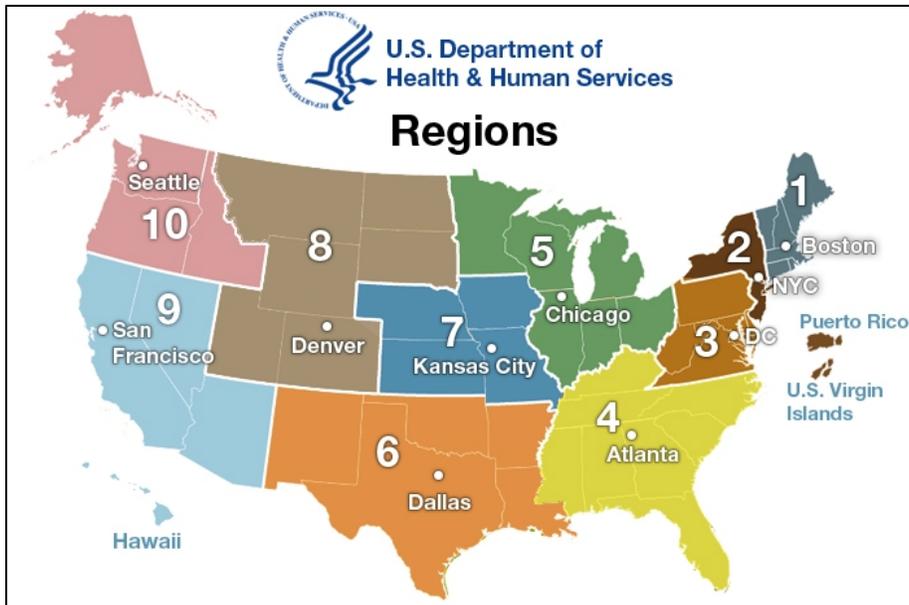


INTERNATIONAL SOCIETY
FOR DISEASE SURVEILLANCE

Syndromic Surveillance Regional Data Sharing Workshop: HHS Region 5

Final Report

International Society for Disease Surveillance



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Syndromic Surveillance Regional Data Sharing Workshop: HHS Region 5

Final Report

Table of Contents

Acknowledgements	3
Executive Summary	4
Background	4
Workshop Description	5
<i>Public Health Participants</i>	5
<i>Objectives and Target Outcomes</i>	6
<i>Timeline</i>	6
<i>Workshop Approach</i>	6
Workshop Evaluation	7
<i>Evaluation Approach and Methods</i>	7
Workshop Results	9
<i>Participant Knowledge and Skill</i>	9
Data Processing Knowledge.....	10
Data Analysis and Interpretation Knowledge.....	10
Communicating Syndromic Surveillance Information Knowledge.....	11
Data Quality Assurance Knowledge.....	11
<i>Inter-jurisdictional Data Sharing</i>	11
<i>Logistics and Facilitation</i>	11
<i>Workshop Resources</i>	11
Discussion	12
Conclusions	13

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Executive Summary

Sharing public health data and practices among public health authorities enhances local and regional situational awareness and epidemiological capacities. Although technology is a critical medium for data sharing, positive working relationships and trust must come first.

To promote inter-jurisdictional syndromic surveillance data sharing and facilitate skill development among practitioners, a *Regional Data Sharing Workshop* was developed and piloted by the International Society for Disease Surveillance (ISDS). A non-formal education approach, which stresses self-directed learning and peer-to-peer problem solving, was used to design and plan Workshop activities. The effect of the Workshop on data sharing and participant skills was assessed using quantitative and qualitative methods.

Thirteen surveillance professionals from seven state and local public health agencies in the U.S. Department of Health and Human Service (HHS) Region 5 planned and participated in the 2-day Workshop. The participants selected data sharing for heat-related illness surveillance using BioSense 2.0 as a use case to focus Workshop activities and discussions.

Assessment findings indicated that Workshop participation increased syndromic surveillance data sharing among Region 5 jurisdictions and, furthermore, built new knowledge and skills that advanced surveillance competencies and performance. Survey data showed that 13 new data sharing partnerships are underway or planned as a result of the Workshop. Comparisons of participant responses on a syndromic surveillance skills inventory before and after workshop participation indicated positive gains in skills for:

- Data processing;
- Data analysis and interpretation;
- Communicating syndromic surveillance information;
- Data quality assurance; and
- Establishing data sharing partnerships.

The Regional Data Sharing Workshop is an effective and efficient means for promoting syndromic surveillance data sharing and skill development. With the opportunity to collaborate and discuss data sharing in-person for a specific, regionally relevant purpose, participants strengthened inter-jurisdictional relationships, leading to more data sharing and improved skills that benefit syndromic surveillance work. These results present a strong case for repeating similar workshops in other HHS regions in order to build regional data sharing and to improve public health practice nationwide.

Background

U.S. public health authorities (PHAs) are facing an unprecedented opportunity to build their capabilities in real-time public health surveillance. The specificity and volume of data from emergency department (ED) visits from electronic health record (EHR) technology are growing exponentially due to the Meaningful Use incentive programs. A re-designed BioSense system, as well as open-source solutions, has made state-of-the-art information technologies for public health data management, processing, analysis, and reporting increasingly accessible to PHAs. For every PHA, 100% ED visit coverage is an achievable goal and the tools for analyzing those data are available at an unprecedented level.

Despite these technological advancements, however, meaningful changes in public and population health outcomes remain limited by the capacity of PHAs to utilize the new technologies. At a minimum, PHAs require professionals with basic competencies in public health informatics, syndromic surveillance science, statistical methods, and business practices to use Meaningful Use data for core surveillance activities (e.g., influenza-like-illness surveillance). More advanced public health applications (e.g., chronic disease surveillance) will require a workforce with greater knowledge of EHR data quality, skill in operating novel information technologies, and an enhanced ability to use new surveillance information in public health practice. Public health surveillance practitioners must acquire additional knowledge and skills to unlock the full potential of an array of new and innovative opportunities in public health surveillance.

ISDS, in collaboration with ASTHO, and with the support of the CDC, piloted a Syndromic Surveillance Regional Data Sharing Workshop to assist PHAs in building their capacity to enhance real-time surveillance capabilities with EHR data. This Report describes the design and results of the Workshop and the utility of the format as a model for developing and transferring scientific and technological knowledge and skills among public health surveillance practitioners.

Workshop Description

The Workshop was planned and conducted over three months in 2013. A planning committee advised development of the Workshop approach and evaluation. The Workshop was managed and facilitated by ISDS facilitators, Charlie Ishikawa, MSPH and Becky Zwickl, MPH. ASTHO supported participant travel and lodging and Workshop facilities in Chicago, IL were provided in-kind by RTI International.

Public Health Participants

Among the HHS Regions, Region 5 had the greatest proportion of jurisdictions (five out of six states) participating in and providing emergency department visit data to the nationwide BioSense 2.0 syndromic surveillance program. Organizers



believed that utilizing a common system would facilitate sharing real-time syndromic surveillance data. Therefore, for this initial Workshop, health departments operating syndromic surveillance systems within HHS Region 5 jurisdictions plan were invited to send 1-2 staff to the Workshop (Table 1).

Table 1: HHS Region 5 Participating Jurisdictions

<i>HHS Region 5 State</i>	<i>Participating Jurisdictions</i>
Illinois	<ul style="list-style-type: none"> • Illinois Department of Public Health • Cook County Department of Public Health • Chicago Department of Health
Wisconsin	<ul style="list-style-type: none"> • Wisconsin Department of Health Services
Michigan	<ul style="list-style-type: none"> • Michigan Department of Community Health
Indiana	<ul style="list-style-type: none"> • Indiana State Department of Health • Marion County Public Health Department
Minnesota	<ul style="list-style-type: none"> • N/A
Ohio	<ul style="list-style-type: none"> • Ohio Department of Health

In addition, representatives from the New Hampshire Department of Health and the ISDS Board of Directors participated.

Objectives and Target Outcomes

The Workshop was designed so that by the end, participants would have:

1. Built skills in syndromic surveillance practice;
2. Examined and shared best practices in analytic methods;
3. Developed action steps for establishing inter-jurisdictional data sharing; and
4. Fostered collaboration among the peer network of surveillance professionals.

The target outputs for the Workshop were:

1. Working disease or condition case definitions using electronic emergency department visit data records;
2. Applied and evaluated analysis plans for conditions of interest;
3. Prioritized data sets for sharing;
4. Actionable steps for establishing inter-jurisdictional data sharing; and
5. Other outcomes to be added by participants prior to the Workshop.

Timeline

The Syndromic Surveillance Regional Data Sharing Workshop was planned and conducted over three months in 2013. See Appendix A for Workshop deliverables including the Workshop planning timeline, agenda, participant list, and surveys administered.

Workshop Approach

A non-formal education¹ approach was used to plan and conduct the Workshop. In this learner-centric paradigm, “the learning is instigated through a need for understanding and specific knowledge in an environment of shared inquiry with others, in the search for the most appropriate information.” This approach was believed to be especially

appropriate for this group of adult surveillance professionals who could actively engage in the learning process and extract information to meet their priority needs.

ISDS staff worked with participants through an online survey and planning meetings before the Workshop to identify heat-related illness as a regional surveillance priority that would benefit from data sharing.

The Workshop consisted of two primary activities (See Appendix A for Meeting Agenda):

1. *Data Sharing* – Participants worked to identify best practices in heat-related illness surveillance using regional emergency department visit data and, in so doing, better understand the practical considerations associated with data sharing; e.g., the effect of jurisdictional differences in syndromic surveillance data collection and analysis on data interpretation and response.
2. *Planning for Future Sharing* – Participants worked with the Workshop facilitator to document the benefits, barriers, and solutions to sharing emergency department visit data among jurisdictions in HHS Region 5 and with the CDC.

Workshop Evaluation

Evaluation Approach and Methods

The CDC evaluation framework¹ was used as a model to assess the Workshop process and outcomes. The objectives of the evaluation were:

Objective 1: Measure change in participant knowledge and skill in syndrome-based surveillance methods and technologies due to Workshop participation. As a result of Workshop-associated activities...

- a. What epidemiological, statistical and/or business knowledge did participants gain?
- b. What epidemiological, technical and/or business skills did participants gain?

Metrics:

- Pre- and post- Workshop self-reported measures in syndromic surveillance knowledge and skill in the following areas: Data quality, data management, data processing, statistical analysis, data interpretation, data reporting practices, and public health business practices.
- Document and describe Workshop outputs related to syndromic surveillance science and practice.

¹ Centers for Disease Control and Prevention. Framework for program evaluation in public health. MMWR 1999;48 (No. RR-11): <http://www.cdc.gov/eval/framework/index.htm>

Objective 2: Describe the participants' perceptions of changes in their ability to establish syndromic surveillance data sharing due to Workshop participation. As a result of Workshop associated activities...

- c. What knowledge did participants gain that may aid in establishing data sharing agreements?
- d. What resources did participants acquire that may be useful in establishing data sharing agreements?

Metrics:

- Pre- and post- Workshop self-reported beliefs regarding data sharing and barriers to establishing data sharing agreements
- Document and describe Workshop outputs related to syndromic surveillance data sharing

Objective 3: Assess the extensibility of the Workshop model to other HHS Regions.

- e. What were the tasks and resource utilizations for planning and convening the Workshop?
- f. What is the estimated cost per participant for future Workshop planning?
- g. What actions should be taken to maximize future Workshop quality?

Metrics

- Tasks and person-hours to plan, prepare, convene, and report on the Workshop's findings
- Materials and services used to plan, prepare, convene, and report on the Workshop's findings
- Participant perceptions of venue, planning, preparation, and facilitation quality.

Information gathered from the pre- and post- Workshop surveys, as well as the data sharing follow-up survey, was analyzed using Excel. Quantitative analyses included calculations of:

- Median change in knowledge, skills, and abilities for the participants;
- Calculating median post-Workshop scores on each of the survey questions; and
- An assessment of change in data sharing status.

Qualitative data were analyzed using Dedoose². All notes from the Workshop were uploaded to Dedoose and each excerpt was individually tagged by Workshop objective. One ISDS staff member performed the initial tagging and a second reviewed the groupings to assure inter-rater reliability.

² <http://www.dedoose.com/>

Workshop Results

Table 2 describes the artifacts developed by participants and facilitators during the Workshop.

Table 2: List of documents or artifacts developed during the Workshop.

Name	Description	Location
Lessons learned from Workshop planning and preparation	Lessons and/or observations that participations gained while planning and preparing for the Workshop	Appendix B
Activity #1 Products	Practices in heat related illness (HRI) surveillance: Participants documented common business parameters for conducting HRI surveillance using ED visit data; Useful BioSense 2.0 functionalities; Potential changes to the BioSense 2.0 “heat, excessive” classifier; and factors influencing ED visit data interpretation for HRI surveillance.	
Day 1 Reflections	Participant thoughts about data sharing following Workshop Day 1	
Activity #2 Products	State of readiness for data sharing; and benefits, barriers, and solutions for establishing inter-jurisdictional data sharing	
Next Steps	Participant generated ideas for actions following the Workshop	
Staff Notes	Notes from ISDS and RTI staff regarding the Workshop	

Participant Knowledge and Skill

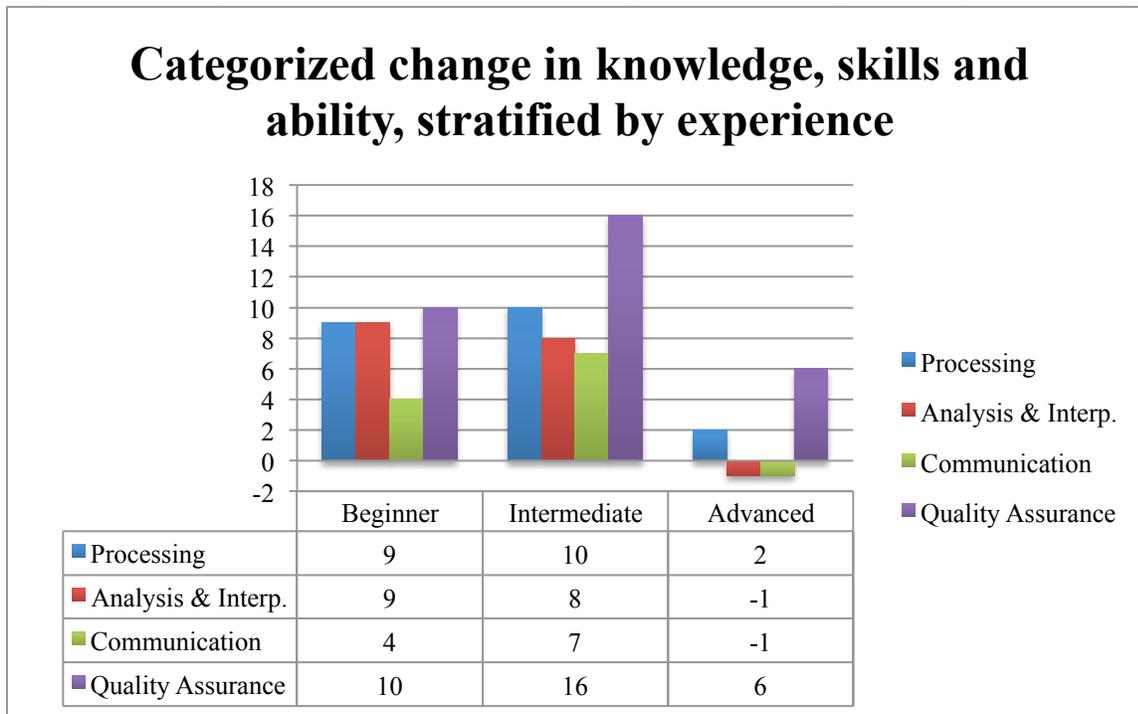
Change in participant knowledge and skill in syndromic surveillance due to the Workshop was measured using an inventory of syndromic surveillance work areas. Immediately before and after the Workshop, participants rated their knowledge, skills or ability in the following work areas:

1. Data processing;
2. Data analysis and interpretation;
3. Communicating syndromic surveillance information;
4. Data quality assurance; and
5. Establishing data sharing partnerships.

Comparisons of pre- and post- Workshop assessment responses indicated that participants, on average, gained substantial knowledge, skills, and ability in the above 5 areas. Each point of change represents either a small growth (positive points) or a small decline (negative points) in knowledge, skills, or ability. For example, a 1 point positive change could indicate a change from “I know about/can do this” to “I know about/can do this well enough to train someone else”. A 1-point negative change could indicate a change in the opposite direction, from “I know about/can do this well enough to train someone else” to “I know about/can do this”. Though growth was

greatest among participants with a beginning level of expertise in syndromic surveillance methodologies, advanced practitioners learned substantial amounts in quality assurance (see Figure 1). Overall, practitioners across experience levels learned the most in data quality assurance.

Figure 1: Categorized and stratified change in knowledge, skills, and ability



On average, Data Quality saw the greatest change per question. In total, participants recorded a 6.4-point average shift per question in the Data Quality Assurance category; this indicates that each participant saw a change of approximately 0.58 points per question in Data Quality Assurance skills. In comparison, they saw only a 0.14-point change per question in Data Analysis and Interpretation.

Participants discussed the following during the Workshop, all of which may have contributed to changes in skill level across the above four categories.

Data Processing Knowledge

Considerations discussed at Workshop:

- Age group of 18-49 is highest risk group of heat-related illness
- 49-64 is also at high risk
- Males are at higher risk for heat-related illness

Data Analysis and Interpretation Knowledge

Considerations discussed at Workshop:

- Event awareness (e.g., marathon)
- Weather
- Population coverage/density

- Urban/rural makeup of population
- Typos can confound analysis and results
- Mortality data
- Over the counter medication

Communicating Syndromic Surveillance Information Knowledge

Considerations discussed at Workshop:

- Syndromic surveillance information should be discussed with:
 - City, state and county executives
 - Hospitals
 - Emergency management
 - Special event managers
 - Public health and government agencies

Data Quality Assurance Knowledge

Considerations discussed at Workshop:

- Many potential issues with adding dehydration to search criteria (will pick up people with GI illness)
- Important to understand context for queries (e.g., if query “hot” may get returns for “gunshot”, particularly in urban areas such as Chicago)
- If you don’t know exactly what is going into a system (BioSense) difficult to properly analyze data
- Updated lists of contributing EDs, including outage listings, are needed

For additional analysis and a detailed breakdown of knowledge, skill, and ability gains, see Appendix C, pages 2-6.

Inter-jurisdictional Data Sharing

Change in data sharing relationships among jurisdictions due to Workshop participation was measured using a post-Workshop survey that asked participants about the state of their inter-jurisdictional data sharing relationships before and after the Workshop. These survey data show that 13 new data sharing partnerships are underway or planned. This includes increases in data sharing with CDC, other states, other BioSense users, and other counties or local jurisdictions. See Appendix C, pages 6-10 for more details on changes in data sharing status.

Logistics and Facilitation

The logistics and facilitation of the pilot Workshop received positive feedback from participants. For more detailed information see Appendix C, pages 12-15.

Workshop Resources

The human and material resources used to plan and conduct the Workshop are described in Figure 2. Since the Workshop was a pilot, a considerable amount of staff time was required to develop the approach and materials. Examples of such materials include: Workshop invitations, a participant orientation, preparation surveys and instructions. Subtracting development work from the total tracked person-time used by

ISDS staff for this Workshop provides an estimate of the person-time required to repeat the Workshop in another HHS Region.

Figure 2: Resources used to plan and conduct the Syndromic Surveillance Regional Data Sharing Workshop in HHS Region 5

Work Breakdown Structure		Tasks	Actual Work ³
<pre> graph LR A[Syndromic Surveillance Data Sharing Workshop] --> B[Task 1: Logistics] A --> C[Task 2: Project Management] A --> D[Task 3: Workshop Evaluation] A --> E[Task 4: Workshop Facilitation] A --> F[Task 5: Report on performance and findings] </pre>		Logistics	14 hours
		Project Management	90 hours
		Workshop Evaluation	27 hours
		Workshop Facilitation	125 hours
		Workshop Report	50 hours
		Materials	Actual Costs
		Handouts	\$100
		Lanyard Name Tags	
		Services	Actual Costs
		Meeting Rooms	In Kind
		Travel, lodging, and food per diem	\$785 ⁴ /participant

Discussion

The Workshop outputs support the results from the pre- and post- Workshop assessments that indicate that the greatest gain in knowledge, skills and ability were in the data quality assurance category. There was substantial discussion of how data quality affects the ability to share data between jurisdictions. This ended up being a core issue, because jurisdictions feared sharing their own data if the quality was not high, and also did not want to receive low quality data from other jurisdictions.

Additionally, participants recorded increased levels of inter-jurisdictional sharing of data for syndromic surveillance. There was new interest in data sharing at the regional level (i.e., between participating jurisdictions), but also at the federal level (e.g., with BioSense). These increases in data sharing capacity and interest reflect conversations on the myriad different ways in which data sharing can benefit syndromic surveillance. They may also be partially attributed to the face-to-face Workshop setting, which allowed participants to build relationships with each other and discuss the logistics of data sharing.

Finally, the purpose of this Workshop was partially to assess its effectiveness and applicability to other settings. Participants voiced support for future meetings and described substantial benefits to face-to-face meetings on a regional basis. In particular, they noted that regional similarities and geographic continuity make the smaller Workshop worthwhile and effective. In fact, participants elected to have follow-up teleconferences to discuss regional relationships and have continued communicating via an online forum group.

³ Excludes development hours (e.g., work to create surveys, instructions, and activity plans)

⁴ Average for participants only (i.e., persons from agencies within Region 5)

Conclusions

Based on the evaluation data, the Regional Data Sharing Workshop was an effective and efficient means for promoting syndromic surveillance data sharing and learning. The opportunity for face-to-face discussions of data sharing for a specific purpose strengthened important relationships among participants from neighboring jurisdictions and will apparently lead to more effective data sharing and regional syndromic surveillance. Participant feedback was positive and significant gains were recorded in knowledge, skills, and abilities related to syndromic surveillance.

One notable outcome of the Workshop was a focus from participants on maintaining the regional partnership and overcoming barriers to effective data sharing. In the Next Steps document in Appendix B (pp. 16-18) some key processes are outlined, including addressing BioSense Governance with a list of desired tools and functionalities, and developing an online community forum to continue the conversations started at the Workshop. Developing *Next Steps* as a group served as a catalyst for sustained communication and data sharing.

The Region 5 pilot demonstrates that this model for dissemination and implementation is both extensible and applicable to other regions and that funding to conduct similar workshops in other HHS Regions is warranted.

Appendix 2: Letter to BioSense Governance Board

September 12, 2013

The BioSense Governance Group
c/o Scott Gordon, PhD
Association of State and Territorial Health Officials
sgordon@astho.org

Re: Recommendations for improving BioSense's data sharing capability

Dear BioSense 2.0 Governance Group:

The following letter is intended to establish a dialogue between surveillance professionals and the BioSense Governance Group. We are interested in establishing data sharing relationships across jurisdictions utilizing BioSense. Within this letter are a number of recommendations for increasing the feasibility of this data sharing process in BioSense. Recommendations include: 1) increased documentation and additional tools; and 2) functionalities in the BioSense application. In addition, we request a continued conversation with the BioSense Governance Group and a forum through which to address these and future recommendations.

On May 20-21, 2013, the International Society for Disease Surveillance (ISDS), with the support of the Association of State and Territorial Health Officials (ASTHO), convened a Workshop of jurisdictions (ISDS Data Sharing Workshop), mainly from Region 5 of the Department of Health and Human Services (HHS). The two-day Workshop brought public health professionals working in syndromic surveillance together to discuss their current syndromic surveillance systems and practice, as well as their desire to share data between jurisdictions. As part of the Workshop process, data sharing was enabled between all participating jurisdictions, which helped to facilitate conversations and identify steps we need to take to establish long-term sharing of syndromic surveillance information. Workshop participants came from the following jurisdictions:

- Illinois Department of Public Health
- Cook County Department of Public Health
- Chicago Department of Health
- Wisconsin Department of Health Services
- Michigan Department of Community Health
- Indiana State Department of Health
- Marion County Public Health Department
- Ohio Department of Health
- New Hampshire Department of Health and Human Service

During the Workshop, we identified several vital public health activities that would benefit from greater syndromic surveillance data sharing among participating jurisdictions. BioSense can be an important tool in building the capacity of public health agencies to share data in near real-time. In particular, data sharing through BioSense can aid our jurisdictions in:

- Cross-border case-finding
- Identifying patterns or trends (local, state, regional, federal)
- Emergency preparedness planning and partner notification
- Mutual aid
- Making sure federal government has complete picture
- Hypothesis generation and testing

In its current state, however, we find that there are resource and functionality gaps that limit our ability to share data within BioSense.

To share some insights gleaned prior to, during, and after the Workshop we present the following as examples of how BioSense could be modified and improved. Incorporating these recommended functionalities and tools will allow our jurisdictions to effectively utilize BioSense for the above syndromic surveillance data sharing.

The following two (2) items are of the highest priority to Workshop participants:

- 1. A user guide that provides practical guidance for using BioSense in practice (including both individually and if data sharing is enabled)**
 - a. Including a description of BioSense algorithms (i.e., how is data binned?)
- 2. Greater and more granular control over what data is shared with whom**
 - Jurisdictions should be notified of any Data Use Agreement (DUA) changes in shared data
 - User level stratification would be useful (e.g., group people as public health practitioners, researchers, etc.; allow users to grant control to any or all of these groups individually)
 - Would like control over granting permission to individual counties within a state (e.g., allow users to grant permission to one county within a state but not all)
 - Ability to assign different levels of access to different users within a jurisdiction

Documentation on the following details is also of high priority to Workshop participants:

- **Documentation that describes the process or procedure by which records are binned and made available for analysis using the front-end BioSense application**
 - Consider posting on Community Forum or similar platform, BioSense application site, or similar platform
 - Would ideally like the ability to look at data pre-binning
- **Documentation (via tooltip) on:**
 - User management control panel
 - Data sharing control panels
 - Line-level export
- **Documentation of metadata, including the description of specific sources that are reporting data (e.g., is it emergency department data only? What are the normal number of ED visits in a day? What proportion of the jurisdictional population is covered?)**
- **Documentation of data quality metrics on the front end, particularly high-level metrics such as completeness of data, percentage of categories captured, etc.**
 - It would be useful to include automated data quality checks—for example, if age data is sent to Biosense but is not showing up on the backend, it should trigger an alert.
 - There needs to be a way to assess the quality of a jurisdiction’s data before including it in shared analysis.
- **Documentation of how RTI is responding to user needs to increase transparency and enable an open dialogue between users and RTI**
- **Documentation of syndrome definitions utilized in BioSense**
 - Including a complete description of inclusion criteria for each BioSense syndrome

Finally, the following tools and functionalities would be beneficial to increasing individual jurisdictional use as well as data sharing through BioSense:

- **Additional data visualization options, including the ability to see the following:**
 - Trends over time in the number of hospitals
 - Trends over time for total report volume
- **Allow users to identify quickly and easily with whom they are sharing data (written documentation requested)**
 - For instance, if a user is sharing data with a state, who within the state can see the data?
- **Permit users to specify information about their data**
 - Individual jurisdictions know their data best. In order to allow other jurisdictions to effectively use their data, it would be useful to have a

short document describing the jurisdictional data and any nuances that may be vital to data interpretation.

- **Feature release notes on incremental changes and fixes**
- **Ability to customize syndromes, including the following:**
 - Ability to use exclusion terms in searching chief complaints
 - Selective sharing by syndrome instead of all data
 - Ability to add custom search terms, including ability to choose what terms to perform a query on (chief complaint, diagnosis code)
 - Delineation of heat exhaustion in the syndrome definition—ICD codes 992.5, 992.6
 - Stratification of classifiers (chief complaint, diagnosis code)
- **Increased data visualization capability**
 - Ability to split compare graphs—tab through graphs, make the data easier to view on one interface
 - Greater granularity of geographic data down to the 5-digit Zip Code level
 - The ability to select and view data from individual sending facilities within a jurisdiction
- **Establish model policies/standard public health practices around protection of confidentiality, with a focus on legal barriers**
 - Could include a standardized DUA for BioSense users

Thank you for taking the time to consider our comments and suggestions. With the recommended modifications, BioSense could become a fully integrated data sharing mechanism that would more effectively benefit syndromic surveillance practice throughout our region.

If you have questions about any of these items, or would like to schedule a follow-up call, please contact Charlie Ishikawa at 617-779-0886 or cishikawa@syndromic.org.

Sincerely,
ISDS Data Sharing Workshop Participants

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Appendix 3: ISDS Annual Conference Roundtable Abstract

Check! Explore Barriers and Solutions to Data Sharing on BioSense 2.0

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Objective

Build upon the findings of a Regional Data Sharing workshop with the larger surveillance community to more clearly describe the benefits, barriers, and needs for data sharing on the BioSense 2.0 platform.

Introduction

Inter-jurisdictional data sharing can enhance disease surveillance capabilities for local, state, regional and national public health situational awareness and response. BioSense 2.0, a cloud-based computing platform for syndromic surveillance, provides participating local, state and federal health jurisdictions with the ability to share aggregated data; a functionality that is easily activated by selecting an administrative checkbox within the BioSense application. Checking the data-sharing box, however, is a considerable decision that comes with benefits and consequences.

On May 20-21, 2013, nine city, county, and state public health department jurisdictions (mainly from the mid-western region of the U.S.) met to explore data sharing for Heat Related Illness (HRI) surveillance using BioSense 2.0. During the workshop, all participants agreed to share data (using the BioSense 2.0 front-end application) in real-time to investigate HRI trends in regional populations during May-August 2012, evaluated HRI case-definitions, and documented benefits and barriers to inter-jurisdictional data sharing. The workshop was convened by ISDS, in collaboration with the Association of State and Territorial Health Officials (ASTHO), with the support of the U.S. Centers for Disease Control and Prevention. Staff from BioSense programmatic and technical teams were also present for the workshop.

Description

This roundtable will build upon the workshop findings to develop recommendations for the BioSense Governance Group. Participants will have the opportunity to modify or add to the workshop's list of perceived barriers to inter-jurisdictional data sharing, develop solutions, and contribute data sharing success stories.

Benefits to data sharing identified at the workshop include:

- Cross-border case-finding
- Identifying patterns or trends (local, state, regional, federal)
- Emergency preparedness planning and partner notification
- Estimating an end to an event, based on declining trends in neighboring areas
- Mutual aid
- Ensuring national situational awareness for federal partners
- Hypothesis generation and testing
- Retrospective analysis to improve public health practice

Barriers to data sharing identified at the workshop include:

- Legal considerations regarding protected health information
- Ambiguity as to whom data is shared with and limited granularity in data sharing controls
- Quality of shared data is unknown introducing biases

Audience Engagement

Is there agreement/disagreement regarding our data sharing benefits? Other benefits to add?

- What barriers do you currently have with sharing data? Solutions to overcome barriers?
- What metadata should be available (and how should it be displayed) to overcome data quality barriers?
- Besides BioSense, does your jurisdiction have other syndromic surveillance systems in place? Is BioSense your primary analytic tool?
- What data quality measures would be integral to proper interpretation of the data?
- Is there agreement or disagreement regarding our recommendations? Other recommendations?
- What user roles, if any, should be identified for data sharing with other jurisdictions?

Conclusions

Data sharing can benefit a range of public health activities including cross-border outbreak detection, identifying regional and federal health trends, and hypothesis generation and testing

- Convening an in-person Workshop facilitated trust and interpersonal relationship building, as well as the initiation of plans for 13 new data sharing permissions among participants (which included shifts from sharing aggregate to line-level data and increased inter-jurisdictional sharing between CDC and local health departments versus between state and local prior to the Workshop)
- Data quality and metadata are key; all data users need to understand the context and quality of the data
- Substantial increases in epidemiological knowledge, skills, and abilities were noted from pre and post workshop assessments
- Legal and privacy concerns can block effective data sharing

Keywords

BioSense; Data Sharing; Collaboration

Acknowledgments

Workshop participants would like to acknowledge the ISDS staff for facilitating the meeting, sponsored by ASTHO and the CDC, with valuable technical feedback from CDC and RTI staff.

*Marcus Rennick

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Appendix 4: Distribute Metadata Collection Tool

Distribute Site Profile

*Codes: 0=No; 1=Yes; 777=Unknown; 999=Null

Purpose: 1) Improve the ability of Distribute participating sites and project partners to understand Distribute data; and 2) serve as a resource for community of practice members to learn from one another. Please review, complete, and correct the information below, and return to distribute@syndromic.org by 4/23/10.

Site ID	Site Name	Type
Site ID	Site Name	Type

System Name	SystemName
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DISTRIBUTE*			Data Sent to Distribute		Strata Sent to Distribute	
DuA	Expiration Date	Average Record Counts	Temperature	Temp	Age	Age
DuA	Expr_Date		Disposition	Dispo	Zip3 Patient	Zip3_P
Transmission		AvgRec_D /d ; AvgRec_W/ w; AvgRec_Yr /Yr	Age Group	AgeGrp	Zip3 Facility	Zip3_F
Route	Frequency		ILI-b	Fever1		
Route	Time Mode		ILI-n	Fever2		
			GI-b	Gastro1		
			GI-n	Gastro2		

SYSTEM COVERAGE		
Facilities in Distribute Feed		
	Facilities sending data to site (n)	Total facilities in coverage area (N)
Emergency Department (ED)	ED	Tot_ED
Pediatric ED	PED	Tot_PED
Urgent Care Facility (UC)	UC	Tot_UC
Pediatric UC	PUC	Tot_PUC
Veterans Administration	VA	Tot_VA
Other	Other	Tot_Other
Notes about facilities	Other_Notes	
Population Coverage		
PopulationCoverage		
Coverage Definition Preferred by Site		Coverage Estimate
SitePrefCoverage		SiteCoverEst1 ; SiteCoverEst2

Site ID	Site Name	Type
Site ID	Site Name	Type

DATA EXCHANGE CAPABILITIES

<i>Please check all that apply</i>		Create & Send			Receive/Process		
		In Use	Capable	Future	In Use	Capable	Future
Content/Messaging	HL7 2.3.1	CS1	CS2	CS3	RP1	RP2	RP3
	HL7 2.5.1	CS1	CS2	CS3	RP1	RP2	RP3
	Other, specify	CS1	CS2	CS3	RP1	RP2	RP3
File Format	Delimited flat file (e.g.CSV)	CS1	CS2	CS3	RP1	RP2	RP3
	XML	CS1	CS2	CS3	RP1	RP2	RP3
	GIPSE	CS1	CS2	CS3	RP1	RP2	RP3
	Other, specify	CS1	CS2	CS3	RP1	RP2	RP3
Transport	FTP	CS1	CS2	CS3	RP1	RP2	RP3
	sFTP	CS1	CS2	CS3	RP1	RP2	RP3
	PHIN MS	CS1	CS2	CS3	RP1	RP2	RP3
	NHIN Gateway	CS1	CS2	CS3	RP1	RP2	RP3
	Other, specify	CS1	CS2	CS3	RP1	RP2	RP3

ANALYTIC TOOLS & SERVICES

Visualization & Analysis Software		
	In Use	Future
BioSense	BioS	
ESSENCE	ESS	
RODS	ROD	
EARS	EAR	
AEGIS	AEG	
Other, specify		

Service Providers		
Provider	In Use	Future
HMS	HMS	
ORION	ORIN	
Other	Other	
Notes	ToolNotes	

NOTES

Notes

Site ID	Site Name	Type
Site ID	Site Name	Type

SYNDROME DEFINITIONS

Syndrome Name	Data Field(s)	Inclusion Terms	Exclusion Terms	Evaluation
ILI-Broad (Sensitive)	ILISynField	ILI-B_IS	ILI-B_NOT	ILI_EVAL
ILI-Narrow (Specific)	ILISynField	ILI-N_IS	ILI-N_NOT	ILI_EVAL
GI-Broad (Sensitive)	ILIGIField	GI-B_IS	GI-B_NOT	GI_EVAL
GI-Narrow (Specific)	ILIGIField	GI-N_IS	GI-N_NOT	GI_EVAL

RETURN TO COMPLETED: distribute@syndromic.org

TERM DEFINITIONS/EXPLANATIONS

DISTRIBUTE: What data is ISDS Distribute receiving from the site?

SYSTEM COVERAGE: What is the generalizability of the data from a site (i.e., description and proportion)?

Population Coverage: This is the response that was collected from site contacts during the Meta-data project. The question is, “What proportion of the catchment area’s population is covered by the data?” Key to answering this question is explaining how the site define’s their catchment area (i.e., geographically).

Coverage Definition Preferred by Site: What is the measure of coverage that people who run the syndromic surveillance system use? This may differ from one site to the next

SYNDROME DEFINITIONS: How does the site classify patient encounters in to syndromes?

Data Fields: What field/variable in the raw data are the basis for syndrome classification?

Inclusion Terms: What terms classify a patient encounter or visit as part of the syndrome group?

Exclusion Terms: What terms ensure that a patient encounter or visit is not misclassified as the syndrome?

Evaluation: How often does the site review the validity of the syndrome definition?