

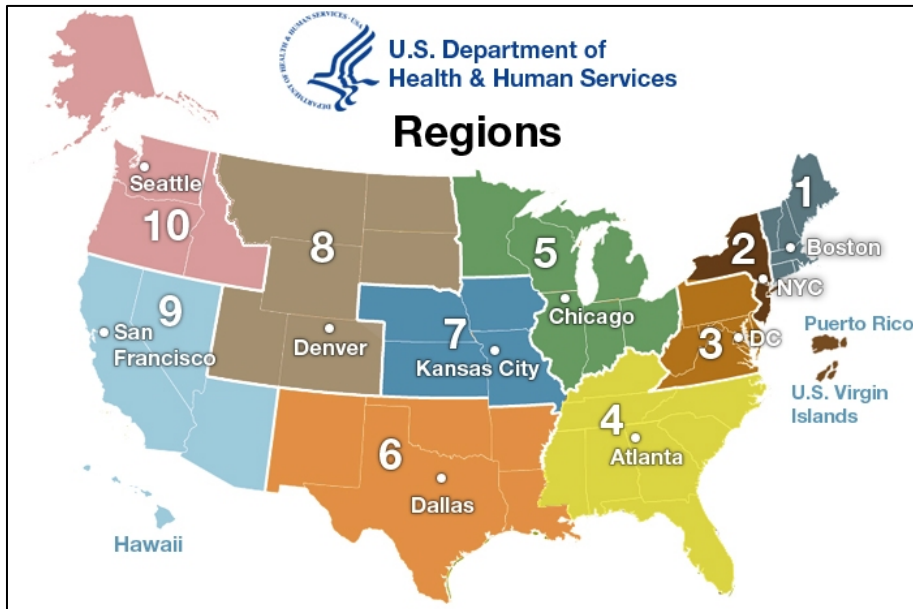


INTERNATIONAL SOCIETY
FOR DISEASE SURVEILLANCE

Syndromic Surveillance Regional Data Sharing Workshop: HHS Region 5

Final Report

International Society for Disease Surveillance



For questions about this report, please contact:

Charlie Ishikawa, MSPH
Associate Director, Public Health Programs
ISDS
cishikawa@syndromic.org

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Workshop Participants

Planning committee

Umed Ajani
Jim Collins
Kathy Gallagher
Scott Gordon
Charlie Ishikawa
Dave Swenson

Centers for Disease Control and Prevention (CDC)

Umed Ajani
Kathy Gallagher

Association of State and Territorial Health Officials (ASTHO)

Scott Gordon
Paula Soper
Lindsay Strack

BioSense Redesign Team

Nabarun Dasgupta

RTI International

Joyce Andrejack
Shellery Cunningham

ISDS Team

Charlie Ishikawa
Amanda Schulte
Laura Streichert
Becky Zwickl

ISDS Board of Directors

Richard Hopkins (President)

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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

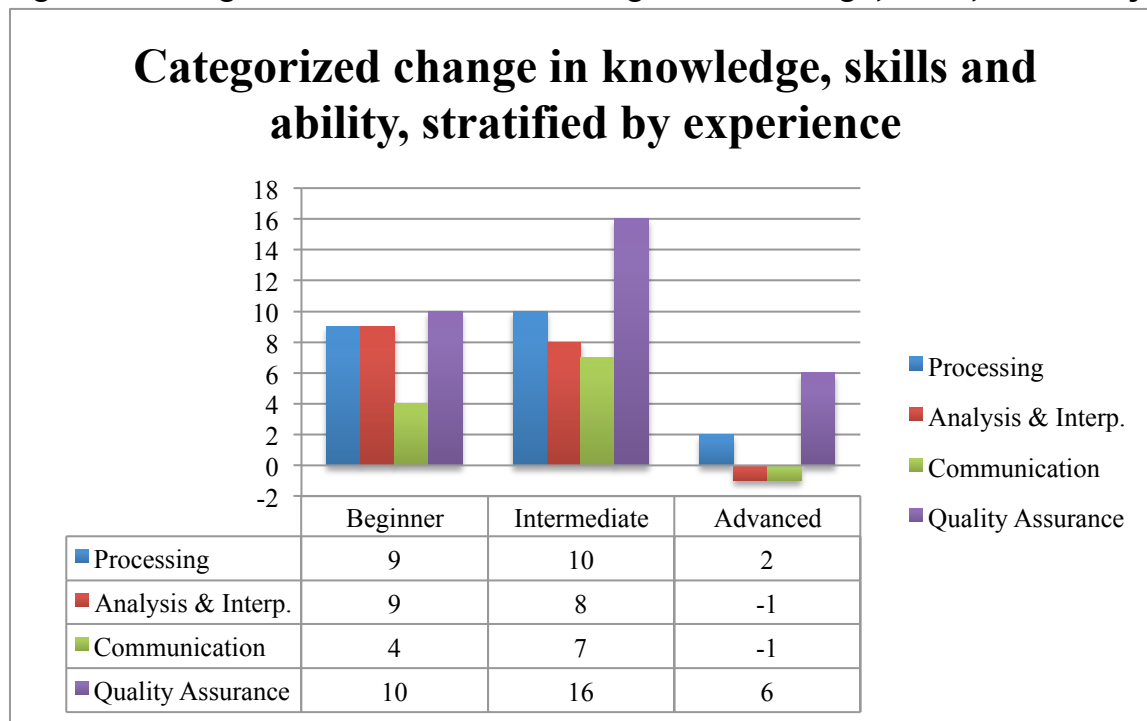
Change in participant knowledge and skill in syndromic surveillance due to the Workshop was measured using an inventory of syndromic surveillance work areas. Immediately before and after the Workshop, participants rated their knowledge, skills or ability in the following work areas:

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

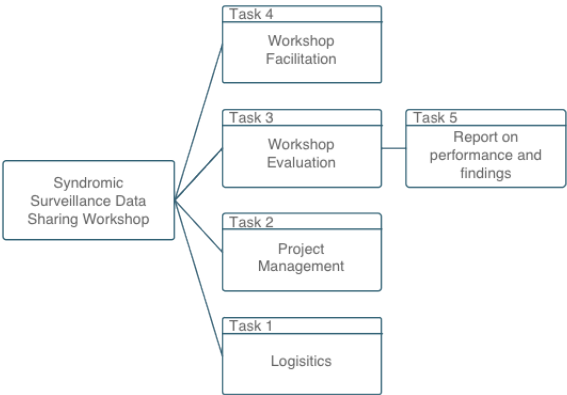
The logistics and facilitation of the pilot Workshop received positive feedback from participants. For more detailed information see Appendix C, pages 12-15.

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 Project Management Workshop Evaluation Workshop Facilitation Workshop Report	14 hours 90 hours 27 hours 125 hours 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.