Regional Syndromic Surveillance Data Sharing Workshop

HHS Region 1 Workshop Report

April 2014

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Regional Syndromic Surveillance
Data Sharing Workshop
HHS1 – Final Report

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Acknowledgements

ISDS would like to thank the following people for their work to make the HHS Region 1 Syndromic Surveillance Data Sharing Workshop a success.

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Akshar Patel, Rhode Island Dept of Health
Chelsea Dubie, Vermont Dept of Health
Dave Swenson New Hampshire Dept of Health
Jenn Evans, Boston Public Health Commission
Jim Lucht, Rhode Island Dept of Health
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Aaron Kite-Powell (Vice-President, Board of Directors)

This work supported by CDC funds to ISDS through a cooperative agreement to ASTHO.
Executive Summary
Sharing public health data and practices among public health authorities enhances epidemiological capacities and expands situational awareness at multiple levels. While the value of inter-jurisdictional data sharing is broadly accepted, there are a number of technological, regulatory, political, and social barriers to overcome before sharing can become a routine part of syndromic surveillance practice.

In order to expand inter-jurisdictional data sharing where it is both permitted and serves the greatest purpose for public health, the International Society for Disease Surveillance (ISDS) and Charles Ishikawa & Associates, LLC, in partnership with the Association for State and Territorial Health Officials (ASTHO), and with funding from the Centers for Disease Control and Prevention (CDC), designed a Workshop for public health officials to discuss and practice inter-jurisdictional data sharing at the HHS regional level¹.

Surveillance professionals from six states and one local public health agency in the U.S. Department of Health and Human Services (HHS) Region 1 planned and attended the 2-day Workshop. Workshop attendees elected to explore how data sharing can support influenza-like illness (ILI) surveillance between regional jurisdictions, and the core activity on Day 1 focused on that purpose.

Over the course of the Workshop, participants discussed their current and ideal practices for ILI surveillance, as well as their data sharing hopes as they relate broadly to syndromic surveillance. By discussing a particular surveillance purpose in-depth, participants were able to conceptualize the abstract idea of data sharing and apply it to real-life practice.

Outcomes determined by comparisons of pre- and post-Workshop assessments showed that participants gained knowledge, skills, and abilities in the following areas:

- Data processing;
- Data analysis and interpretation;
- Communication syndromic surveillance information;
- Data quality assurance; and
- Establishing peer networks and regional collaborations to encourage future data sharing.

This Workshop showed once again that face-to-face interaction is key to promoting inter-jurisdictional collaboration. Although cooperation and data sharing can be promoted through virtual technologies, this model forces important discussions about barriers, solutions, and concerns that are difficult to address otherwise. Future Workshops will continue to work on establishing trust through in-person meetings and nurturing that trust through sustained inter-jurisdictional cooperation.

¹ Region as defined by the U.S. Department of Health and Human Services <http://www.hhs.gov/about/regionmap.html>
Background

Inter-jurisdictional sharing of syndromic surveillance data expands the representativeness and utility of syndromic surveillance data in a number of ways. Local and state jurisdictions have acknowledged a number known benefits to data-sharing that 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.

Public health agencies, however, are often hesitant or incapable of sharing jurisdictional health data. While, on one hand, this hesitancy or caution is in keeping with their duty to secure and safeguard personally identifiable health information, on the other hand, there are instances where data sharing among jurisdictional health agencies is permitted and in the best interests of public health practice. BioSense 2.0 provides public health agencies with information technologies that allow inter-jurisdictional syndromic surveillance data sharing at either an aggregate or patient visit record level. However, despite technological accessibility and a broad recognition of the mutual benefits to situational awareness, many jurisdictions have elected not to share data.

Although technological capabilities such as those available in BioSense 2.0 are critical for data sharing, positive working relationships and trust among surveillance colleagues are foundational. Furthermore, collaborative learning and problem solving experiences are building blocks of strong, collegial, and action-oriented interagency relationships.

To address some of the factors that impede successful inter-jurisdictional data sharing, and to facilitate interagency relationships, the International Society for Disease Surveillance (ISDS) and Charles Ishikawa & Associates, LLC, in partnership with the Association for State and Territorial Health Officials (ASTHO), and with funding from the Centers for Disease Control and Prevention (CDC), designed a Workshop for public health officials to discuss inter-jurisdictional data sharing at the HHS regional level. A pilot Workshop held in May 2013 successfully established long-term cooperation between regional jurisdictions in HHS Region 5, increasing knowledge, skills, and abilities in syndromic practices, and facilitating information sharing.

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3 Region as defined by the U.S. Department of Health and Human Services
<http://www.hhs.gov/about/regionmap.html>
This Report focuses on the second Syndromic Surveillance Data Sharing held in HHS Region 1. As with the pilot Workshop, the ultimate purpose of the HHS 1 workshop was to work towards inter-jurisdictional data sharing. However, incremental goals were equally important, including:

- Establishing cooperation and trust between regional jurisdictions;
- Providing face-to-face contact to introduce and build relationships between individuals;
- Understanding other jurisdiction’s common practices with syndromic surveillance systems; and
- Increasing understanding of BioSense 2.0’s functionalities as a syndromic surveillance data sharing tool.

**Workshop Description**

The Region 1 Syndromic Surveillance Data Sharing Workshop (Workshop) was held on February 27-28, 2014 at the offices of RTI International in Waltham, MA. Workshop planning began in January 2014 and follow-up activities continued through March 2014. Additional details regarding the Workshop timeline, agenda, participant list, and assessments are located in Appendix A.

The project was managed by Becky Zwickl, MPH and Laura Streichert, PhD, MPH (ISDS), with the Workshop planning and activities facilitated by Charlie Ishikawa, MSPH (Charles Ishikawa & Associates, LLC.), under contact to ASTHO, who also participated in planning (Scott Gordon, PhD). RTI International made an in-kind contribution of facilities for the Workshop, as well as provided technical support for BioSense 2.0 related work.

**Public Health Participants**

Workshop participants came from six states and one local public health agency in HHS Region 1. These jurisdictions were: Connecticut, New Hampshire, Maine, Massachusetts, Rhode Island, Vermont, and the city of Boston (Table 1). These agencies maintain or use systems with varying syndromic surveillance capabilities, and were at different stages in adopting BioSense 2.0 technologies. Regardless of differences in surveillance capabilities, all the jurisdictions perform or have access to a core level of syndromic surveillance data and analyses that made their participation in the Workshop possible.

**Table 1: HHS Region 1 Participants**

<table>
<thead>
<tr>
<th>HHS Region 1</th>
<th>Participating Jurisdiction(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connecticut</td>
<td>• Connecticut Department of Public Health</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>• New Hampshire Department of Health and Human Services</td>
</tr>
<tr>
<td>Maine</td>
<td>• Maine Department of Health and Human Services</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>• Boston Public Health Commission</td>
</tr>
<tr>
<td></td>
<td>• Massachusetts Department of Public Health</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>• Rhode Island Department of Health</td>
</tr>
<tr>
<td>Vermont</td>
<td>• Vermont Department of Health</td>
</tr>
</tbody>
</table>
In addition to the participants, personnel from the CDC, the ISDS Board of Directors, ASTHO, and MIT Lincoln Laboratory were present during the Workshop as observers.

**Objectives and Target Outputs**

The objectives of the Workshop were to have participants:

1. Build skills in syndromic surveillance practice.
2. Examine and share best practices in syndromic surveillance methods.
3. Develop action steps for establishing inter-jurisdictional data sharing.
4. Foster peer-to-peer collaborations in a regional network of surveillance professionals.

Outputs targeted for development during the Workshop included:

1. Actionable next steps for continuing the inter-jurisdictional cooperation.
2. Applied and evaluated analysis plans for condition of interest.
3. Prioritized methodology of syndromic surveillance for condition of interest.

**Workshop Approach**

A non-formal education\(^4\) approach was used to plan and conduct the Workshop. Non-formal education is especially applicable in Workshops such as this one where adult professionals can actively engage in the learning process and extract information to meet their priority needs.

Workshop staff worked with participants to identify a regional surveillance priority that would benefit from data sharing. The Workshop consisted of two activities (See Appendix A for full agenda):

1. *Data Sharing* – Participants worked to identify best practices in influenza-like illness (ILI) surveillance using regional health center visit data with an aim of better understanding 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 health center visit data among jurisdictions in HHS Region 1 and with the CDC.

**Workshop Evaluation**

**Evaluation Approach and Methods**

Workshop processes and outcomes were assessed using the CDC evaluation framework.\(^5\) The evaluation had three main objectives:

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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...
  • What epidemiological, statistical, and/or business knowledge did participants gain?
  • What epidemiological, statistical, and/or business skills did participants gain?

Metrics
  • Pre- and post- Workshop assessments measuring syndromic surveillance knowledge and skills in the following task areas: Data quality; data management; data processing; statistical analysis; data interpretation; data reporting processes; and public health business practices.
  • Document and describe Workshop outputs related to syndromic surveillance science and practice.

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...
  • What knowledge did participants gain that may aid in establishing data sharing agreements?
  • What resources did participants acquire that may be used in establishing data sharing agreements?

Metrics
  • Pre- and post- Workshop assessments measuring beliefs regarding data sharing and barriers to establishing data sharing agreements.
  • Document and describe Workshop outputs related to syndromic surveillance data sharing.

Objective 3: Focus on continuous quality improvement for future Syndromic Surveillance Data Sharing Workshops by assessing...
  • What actions should be taken to maximize future Workshop quality?
  • What were the tasks and resource utilizations for planning and convening the Workshop?

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, communication, preparation, and facilitation quality.

Information gathered from the pre- and post- Workshop assessments was analyzed using Excel. Quantitative analyses included calculations of:
  • Average change in knowledge, skills, and abilities, per category;
  • Median change in knowledge, skills, and abilities, stratified by level of experience with syndromic surveillance practice and methodologies; and
  • Questions with most total gain in knowledge, skills, and abilities, per category.
Qualitative data were reviewed by staff and facilitators, discussed, and, where applicable, will be addressed in future Workshops.

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

Table 2: Documents and artifacts developed during the Workshop

<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lessons learned from Workshop planning and preparation</td>
<td>Lessons and/or observations that participants gained while planning and preparing for the Workshop</td>
<td>Appendix B – Workshop Notes</td>
</tr>
<tr>
<td>Activity #1 Products</td>
<td>Practices in influenza-like illness (ILI) surveillance, including: common business practices; potential changes to BioSense 2.0 classifier; and factors influencing ILI visit data interpretation</td>
<td></td>
</tr>
<tr>
<td>Day 1 Reflections</td>
<td>Participant thoughts at the conclusion of Day 1, looking to Day 2</td>
<td></td>
</tr>
<tr>
<td>Activity #2 Products</td>
<td>Summary of discussion surrounding barriers and possible solutions to data sharing</td>
<td></td>
</tr>
<tr>
<td>Next Steps</td>
<td>Participant-generated ideas for actions following the Workshop</td>
<td></td>
</tr>
</tbody>
</table>

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, each of the 12 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

In comparing pre- and post-Workshop skill inventory measurements, each point of change represents either a small growth (positive points) or a small decline (negative points) in a given area of knowledge, skill, 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”.
The total change in knowledge, skills, and abilities was:

- Data processing – 53 points (6 questions)
- Data analysis and interpretation – 40 points (10 questions)
- Communicating syndromic surveillance information – 15 points (4 questions)
- Data quality assurance – 10 points (5 questions)

On average, Workshop participants made meaningful gains in their syndromic surveillance knowledge, skills, and abilities due to Workshop participation across all four areas (Figure 1). Beginner practitioners saw large gains in two categories: data processing and communicating syndromic surveillance information. Intermediate practitioners saw a similar large gain in the area of data processing. There was only one practitioner who self-rated as “Advanced”, and that practitioner reported loss in knowledge, skills, and/or abilities in the analysis and interpretation category and a fairly steady level of knowledge across the other three categories.

Beginner, intermediate, and advanced rankings were assigned based on three factors: years of experience working in syndromic surveillance; mastery of syndromic surveillance methods; and mastery of syndromic surveillance classifier development. All information was self-reported by participants.

**Figure 1: Change in the knowledge, skills, and abilities of Workshop participants (N=12 participants)**

<table>
<thead>
<tr>
<th>Area</th>
<th>Beginner</th>
<th>Intermediate</th>
<th>Advanced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Processing</td>
<td>1</td>
<td>0.8</td>
<td>0.2</td>
</tr>
<tr>
<td>Analysis &amp; Interp.</td>
<td>0.6</td>
<td>0.4</td>
<td>-0.3</td>
</tr>
<tr>
<td>Communication</td>
<td>0.9</td>
<td>0.1</td>
<td>0</td>
</tr>
<tr>
<td>Quality Assurance</td>
<td>0.1</td>
<td>0.3</td>
<td>0</td>
</tr>
</tbody>
</table>
Specifically, Figure 1 shows beginner, intermediate, and advanced participants in syndromic surveillance work as a proportion of their self-perceived competence in data processing, analysis, interpretation communication and quality assurance tasks as measured before and immediately following the Region 1 syndromic surveillance data sharing Workshop.

Self-perceived changes in competency due to Workshop participation are mainly attributable to the discussions that participants had around either the Day 1 data sharing activity or in making plans to advance regional data sharing in Day 2. In each of the areas assessed before and after the Workshop, discussions of the following topics may have advanced participant learning:

**Data Processing Knowledge**
- 2013-2014 season saw unusually high percentage of cases in 18-49 year old age group
- Normal flu seasons see highest risk in young children and older adults over 65 years of age

**Data Analysis and Interpretation Knowledge**
- General trend that influenza-like illness spreads across the United States from southwest to northeast
- Population density contributing to higher rates of flu and faster rates of transmission
- Local syndrome definitions for tracking influenza-like illness vary from sensitive CDC definition to more specific Acute Respiratory Infection syndrome
- Understanding syndrome definition differences affects data and analytic interpretation
- Data cleaning processes

**Communicating Syndromic Surveillance Information Knowledge**
- How jurisdictions currently share, and would ideally share, information on ILI in their jurisdiction
- How ILI trend data is reported to the public (if applicable)
- Process for discussing ILI trends with media

**Data Quality Assurance Knowledge**
- Misspellings affecting data quality (e.g., the term “influence” being picked up with “flu” in a classifier)
- Understanding other jurisdiction’s data processes

For additional analysis and a detailed breakdown of knowledge, skills, and ability gains, see Appendix C.

**Inter-jurisdictional Data Sharing**
In general, syndromic surveillance data are shared among HHS Region 1 health agencies either in aggregate form in select national public health surveillance programs (e.g., ILI-net), or on an _ad hoc_ basis among peers that know one another. While this general sense of the state of inter-jurisdictional syndromic surveillance data sharing in HHS Region 1 was gained during the Workshop, a more specific measurement was not made. However, given the plans that
participants made during Day 2, which were detailed and assigned to individuals for accountability, it can be said that the Workshop did promote the relationships and actions that are necessary in establishing and advancing data sharing.

**Logistics and Facilitation**
Overall, Workshop participants were satisfied with the Workshop facilitation and logistics. Based on their feedback, future Workshops can be improved by: streamlining communications and emphasizing importance; ensuring participants know the time commitment involved before the Workshop; and considering a warm-up activity that allows participants to get to know one another a bit better. More detailed data is provided in Appendix C.

**Discussion**
Data Sharing Workshop participants made the greatest gain in the area of data processing knowledge. At the Workshop, there was a focus on current flu trends in each of the participating jurisdictions and understanding local syndrome definitions. There was less discussion of data quality, communicating syndromic surveillance information, and analysis and interpretation, which may explain the lower rate of increased knowledge and skills in those areas.

The greatest average gains occurred among practitioners who rated themselves as beginners. This is to be expected given the collaborative nature of the Day 1 data sharing activity and close contact with peers who have greater competency in syndromic surveillance. Interestingly, there was a loss of knowledge, skills, and abilities in the advanced practitioner’s ability to analyze and interpret data. Given staff familiarity with this individual, this change may have resulted from an increase of awareness of the breadth of knowledge or skills related to data analysis and interpretation.

The Workshop participants made significant gains towards inter-jurisdictional cooperation that may lead to data sharing. Since some of the jurisdictions do not currently utilize BioSense 2.0, there will be a technological barrier to establishing real-time inter-jurisdictional data sharing for some agencies. Plans such as those that committed the participants to a comparison of home ILI definitions and establishing an ongoing forum for communication will support future collaborations that are the basis for data sharing.

**Conclusion**
Face-to-face interaction is key to promoting inter-jurisdictional collaboration. Although such cooperation and data sharing can be promoted through internet-enabled or virtual technologies, this model forces important discussions about barriers, solutions, and concerns that are difficult to address otherwise. Equally important was the resulting trust among jurisdictions. Participants and facilitators all noted the importance of this face-to-face communication in establishing future data sharing.

A primary outcome of this Workshop was the articulation of next steps towards data sharing, with a focus on continuing the comparison of local syndrome definitions, analyses, and
interpretations. Participants volunteered to gather and consolidate this information and share it with their colleagues. They also expressed an interest in reconvening and discussing additional next steps in the weeks following the Workshop. This move towards a self-sustaining, involved community is a promising sign for continued data sharing collaboration in the region.