Regional Syndromic Surveillance Data Sharing Workshop

HHS Region 10 Workshop Report

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# Regional Syndromic Surveillance Data Sharing Workshop

**HHS Region 10**  
**Workshop Report**

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Executive Summary

The utility of syndromic surveillance for situational awareness beyond the local level requires data sharing across jurisdictions. The BioSense 2.0 application enables data sharing capabilities through the application interface that is technically easy, (i.e., the click of a button) and uses standard syndrome definitions. While this has great potential for creating a nationwide picture of population health, there is tremendous resistance to data sharing. According to a report written based on discussion among public health practitioners, the primary barriers to data sharing are legal concerns, unknown data quality, and data access issues.¹

To address these barriers and to facilitate inter-jurisdictional relationships in order to promote data sharing and increase practitioner skills and knowledge in syndromic surveillance methodologies, the International Society for Disease Surveillance (ISDS), Charles Ishikawa & Associates, LLC, and the Association of State and Territorial Health Officials (ASTHO) have developed and delivered four regional data sharing Workshops. These have been done in collaboration with the CDC, which provided funding for the project. This Report summarizes the process and outcomes of the fourth Workshop, held in HHS Region 10 in May 2014.

The HHS Region 10 workshop engaged nine participants from state and local public health departments in Idaho, Oregon, and Washington with experience in syndromic surveillance that ranged from less than 1 year to over 10 years. Representatives from Alaska, which is also in HHS Region 10, were unable to participate. Because the participants did not have access to actual emergency department (ED) syndromic surveillance data for sharing, the focus of the workshop was on building inter-jurisdictional understanding and sharing of practices.

On Day 1 of the Workshop participants discussed their syndromic surveillance systems, both existing and planned, and how those systems can be leveraged to promote inter-jurisdictional data sharing. On Day 2, they focused on specific barriers to data sharing, mainly data quality, and identified specific projects to tackle as a group, including sharing of implementation guides that indicate the data elements collected and their format and the development of common syndrome definitions for ILI. The data quality concerns were split into two main groups: data quality when onboarding a system, and data quality after the system is up and running. Many potential projects in both areas were proposed and discussed in relation to their ability to support inter-jurisdictional data sharing.

A comparison of pre- and post-workshop surveys indicated that over the course of the workshop participants reported quantitative gains of knowledge, skills, and abilities.

across four categories of syndromic surveillance methodology: Data Processing Knowledge; Data Analysis and Interpretation; Communicating Syndromic Surveillance Information; and Data Quality Assurance. The group spoke specifically about data processing, analysis, communication, and data quality and their importance in facilitating ILI surveillance, specifically.

In addition, participants spent substantial time discussing inter-jurisdictional data sharing, including regional barriers and potential solutions to those barriers. These conversations allowed participants to outline concrete ways to share data and, perhaps more importantly, also contributed to increased trust between jurisdictions. Many of the participating jurisdictions had never sat in a room with one another to talk about syndromic surveillance. The participants reported that the conversation was valuable and will hopefully lead to long-term collaboration.

Background
Each of the regional data sharing workshops is tailored to meet the priorities, interests, and capabilities of the participating jurisdictions. For the prior three Workshops in HHS Regions 1, 5, and 6, the majority of participating jurisdictions had ready access to Emergency Department (ED) syndromic surveillance data that they were able to utilize at the Workshops for a sample use case. Using their data, participants developed aggregate data sets and graphs that allowed them to compare their home system data with analyses of the same data in BioSense 2.0. This in turn led to substantial conversations about the benefits of syndromic surveillance data sharing both through home systems and through the BioSense system.

In Region 10, some existing syndromic surveillance systems were down during the planning process and the Workshop itself. Additionally, some jurisdictions were in the process of implementing and onboarding their systems. As a result, this Workshop focused more on developing inter-jurisdictional relationships and specific topics (i.e., data quality) than the prior Workshops. The in-depth conversations provided a platform to identify the benefits to inter-jurisdictional data sharing, once the systems are in place.

Workshop Description
The Region 10 Syndromic Surveillance Data Sharing Workshop (Workshop) was held on May 19-20, 2014 at the offices of the Seattle & King County Public Health Department in Seattle, WA. 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); workshop planning and activities were facilitated by Charlie Ishikawa, MSPH (Charles Ishikawa & Associates, LLC.), under contact to ASTHO, who also participated in planning (Scott Gordon, PhD). Seattle & King County Public Health made an in-kind contribution of facilities for the Workshop.
Public Health Participants
Workshop participants came from three of the four states in HHS Region 10. The participating jurisdictions were: Idaho, Oregon, Seattle & King County (WA), Washington, and Whatcom County (WA) (Table 1). These agencies maintain or use systems with varying syndromic surveillance capabilities, and were at different stages in adopting BioSense 2.0 technologies. There were also some temporary data access issues during Workshop planning and implementation that limited the ability to participate in the Workshop with real syndromic surveillance data.

Table 1: HHS Region 10 Participants

<table>
<thead>
<tr>
<th>HHS Region 10</th>
<th>Participating Jurisdiction(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Idaho</td>
<td>• Idaho Department of Health and Welfare</td>
</tr>
<tr>
<td>Oregon</td>
<td>• Oregon Health Authority</td>
</tr>
<tr>
<td>Washington</td>
<td>• Seattle &amp; King County Public Health</td>
</tr>
<tr>
<td></td>
<td>• Washington State Department of Health</td>
</tr>
<tr>
<td></td>
<td>• Whatcom County Health Department</td>
</tr>
<tr>
<td>Alaska</td>
<td>• Unable to participate</td>
</tr>
</tbody>
</table>

In addition to the participants, personnel from ISDS, CDC, and ASTHO 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 a condition of interest.
3. Prioritized methodology of syndromic surveillance for conditions of interest.

Workshop Approach
A non-formal education\(^2\) 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 chose to work 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 10 and with the CDC.

**Workshop Evaluation**

Workshop processes and outcomes were assessed using the CDC evaluation framework. The evaluation had three main objectives:

**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?

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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>
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<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>
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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 were asked to rate 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 per person. 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 cumulative change in knowledge, skills, and abilities for 6 participants was 62 points. See Figure 1 for a breakdown by category.

**Figure 1: Cumulative change, by category, of 6 participants**

![Figure 1: Cumulative change, by category, of 6 participants](image)

Participant responses were broken down by category and by level of experience, i.e., beginner, intermediate, and advanced. 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 2 shows the change in knowledge, skills, and abilities recorded by participants as a result of attending the Workshop. The results show that intermediate practitioners gained the most knowledge, skills, and abilities across all four categories, with the greatest amount of improvement in the area of Communicating Syndromic Surveillance
Information. Advanced practitioners also saw the greatest gains in the Communication category.

Interestingly, beginner practitioners saw very minimal gains across all categories. The lack of concrete data used at the Workshop likely contributed to these minimal gains. While intermediate and advanced practitioners may be able to gain skill through more abstract conversations, that is likely more difficult for beginner practitioners.

**Figure 2: Change in the knowledge, skills, and abilities of Workshop participants (N=6 participants). Values are per question and per participant (i.e., cumulative change in data processing category for beginner practitioners was divided by 6: number of questions and 2: number of participants).**

![Figure 2: Change in the knowledge, skills, and abilities of Workshop participants](image)

<table>
<thead>
<tr>
<th></th>
<th>Beginner</th>
<th>Intermediate</th>
<th>Advanced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Processing</td>
<td>0.25</td>
<td>0.5</td>
<td>0.42</td>
</tr>
<tr>
<td>Analysis &amp; Interp.</td>
<td>0.1</td>
<td>0.75</td>
<td>0.4</td>
</tr>
<tr>
<td>Communication</td>
<td>0</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>Quality Assurance</td>
<td>-0.1</td>
<td>0.6</td>
<td>0.6</td>
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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**
- Age group trends in home systems versus BioSense 2.0
Data Analysis and Interpretation Knowledge
- Importance of allowing jurisdictions to interpret their own data (i.e., if sharing data should also share interpretation)

Communicating Syndromic Surveillance Information Knowledge
- Importance of different messaging for different audiences
- Need to share ILI reports with hospitals, especially infection control practitioners
- Need space for annotation if sharing data

Data Quality Assurance Knowledge
- Identify steps you should go through to ensure data is of good quality before sharing with other jurisdictions
- Monitoring data quality vs. data quality tools at time of onboarding – 2 different details, both of which need to be addressed
- All Region 10 jurisdictions could install a route that would take test syndromic message, develop consistency across region

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

Inter-jurisdictional Data Sharing
As noted in the Background section, concrete inter-jurisdictional data sharing was limited at the Region 10 Workshop since systems were down or are still under development. However, participants still spent a substantial amount of time focused on the benefits of data sharing. In some ways, since there was little concrete data to attempt to share, it was easier to focus on the benefits without become stalled discussing the barriers.

Throughout the discussion, participants continually returned to a discussion on data quality. The data quality concerns were split into two main groups: data quality when onboarding a system, and data quality after the system is up and running. Many potential projects in both areas were proposed and discussed in relation to their ability to support inter-jurisdictional data sharing.

Logistics and Facilitation
Overall, participants provided high ratings on the logistics and facilitation of the Workshop. They rated the facilitation highly and all participants responded that they gained a great deal from attending the in-person meeting.

For the next Workshop, staff should consider better tailoring the pre- and post-Workshop assessments based on the current state of the region. Though the assessments showed concrete gains in the Region 10 participants, some areas of knowledge gain could have been better captured quantitatively. For instance, the majority of Day 2 focused on data quality; had staff identified this ahead of time, they could have better tailored the assessments to reflect that aspect of the meeting.

Finally, participants at the Region 10 Workshop expressed that they thought the work was the “right amount”. This is an important point because after prior Workshops
participants have expressed ideas on how the pre-work could be simplified and decreased; thanks to that previous feedback the process was further, and successfully, refined.

**Discussion**

Early-stage adoption and inaccessible syndromic surveillance systems necessitated that the Workshop planning team to quickly adapt the structure of the meeting. Though the Workshop was intended for use in regions that have ready access to data, the success in Region 10 shows that there is some adaptability afforded by the model. Staff were able to arrange the schedule to provide time for in-depth discussions of data quality, which supported data sharing conversations and were of great interest to Region 10 participants. However, Day 1 of the Workshop did not focus on concrete data to the extent initially intended. The conversation did generate excitement around data sharing, but it’s hard to know the reality of how that will play out once the data is available.

Additionally, the participating jurisdictions were at very different stages of syndromic surveillance adoption. Seattle & King County, for instance, has had a system in place for years. The state of Idaho, on the other hand, is only beginning to onboard in BioSense and has not had a previous syndromic system. The differences between jurisdictions allowed both sides to learn from one another, which led to varying opinions and focuses on topics such as data quality. This may in part explain the quantitative increases in syndromic surveillance knowledge, skills, and abilities, even without access to data.

**Conclusion**

Over the last year, since the pilot Workshop in May 2013, Workshop staff have worked to ensure that each Workshop improves on the prior one and addresses the desires of the new participants. Though data access was an issue in Region 10, the Workshop still met its objectives and the outcomes were positive and clearly reflected in both qualitative and quantitative feedback.

The lesson learned from Region 10 is two-fold: one, there is inherent flexibility in this Workshop model that allows it to be replicated in very different regions; and two, though the model is flexible, it is still ideal for jurisdictions to have access to syndromic surveillance data. Going forward for future Workshops, staff should work to ensure that, whenever possible, each jurisdiction has the access they require for the meeting.

With or without access to data, though, the Workshop led to continuing relationships between jurisdictions in Oregon, Washington and Idaho, with a hope to bring Alaska into the fold down the road. There is substantial opportunity for data sharing between Region 10 jurisdictions using both BioSense 2.0 and other home systems and ISDS will continue to facilitate those conversations and encourage ongoing collaboration through follow-up meetings.