Appendix B: Workshop Notes
Day 1 Notes: April 8, 2014

**Introductory Activity**
What was one thing you observed or learned leading up to the Workshop?
- Many different ways of collecting syndromic surveillance data
- Thought we were further along in syndromic surveillance than actually were
- Receiving inquiries for regional data sharing
- Texas does not have mandatory Syndromic surveillance policy/law → very far behind
- Similar problems between jurisdictions, but important to understand differences too
- Advanced use cases for data—i.e., diabetes, has been really interesting
- Lots of diversity across states syndromic practice
- Couldn’t get to age groups attempting to get to with BioSense data
- Amazed by all similarities
- Can learn a lot from state and county level differences
- Interesting to see how different classifiers act on same set of data
- Learning what they don’t know about BioSense

**Activity #1 Debrief**

**Summary**
- Many jurisdictions have similar struggles with IT/funding, workload required to get useful information out of a system

**Group 1 – Influenza-like Illness (ILI)**
- When, why, who should receive reports, additional data sources?
  - Different groups had different time periods when they do ILI reporting, others do it year round
  - H1N1 occurred in the off-season; one reason to monitor year-round
  - Raise awareness, raise vaccination rates
  - Do surveillance year round so you know when it surpasses the baseline
  - Periodicity—do weekly ILI reports during flu season
  - ILI: report goes out to public, physicians, LHDs, IPs, school districts, hospitals
  - Additional data sources: ambulatory visit data, school absenteeism, lab info, pharmacy surveillance, not ever flu case results in an ED visit
Classifiers used—ICD-9, BioSense, home-grown, ESSENCE
- BioSense classifier vs. home classifier showed different age group trends
- Regional report—would contain trend information on a regional basis
- Idea behind BioSense—to have BioSense be the data sharing platform
- BioSense – a jurisdiction can participate and submit aggregate data
- Is there value even if some groups don’t participate in BioSense – YES
- BioSense ILI classifier – overall trend is the same except for with certain age groupings
- Everyone can conform to the BioSense classifier but it may not be the most ideal
- Changes suggested for BioSense
  - State/County/Region → would like geographical regions that are smaller than state but larger than county

**Group 2 – Gastrointestinal Illness (GI)**

- When, why, who should receive reports, additional data sources?
  - Look at data daily
  - Look for multiple alerts over several days
  - Look at geographic/temporal clusters
  - Call infection preventionists
  - Sometimes clinicians call health department to report potential outbreak
  - Cooperate with law enforcement
  - Use syndromic surveillance to confirm extent of outbreaks; identify additional cases (or none)
  - Use syndromic surveillance to alert/advise healthcare providers for tests
  - Partners to notify:
    - Infection preventionists, EDs
    - Emergency managers
    - Calling other local health departments
    - Schools
    - OTC medication purchases
    - Poison control
- Compare/contrast analyses (classifiers)
  - GI classifier in BioSense may not be inclusive enough
  - Geographic resolution—user lower level (e.g., zips or census tracts)
  - Differences in jurisdictions (percentage jumps may occur in more rural counties)
  - Homegrown classifiers may be more sensitive
- Regional report
  - Weekly mean/ percentage of visits to ED that are GI across the region
    - Compare to sub-regions in the graph
  - Use comparable age groups
  - Look for trending in proximal geographical areas
  - Do geospatial analysis across jurisdictions weekly and on demand
- Changes suggested for BioSense
- Common age groups
- Use percentage of ED visits
- Standards of DUAs and reports→ if get down to Zip code, may only have one case, may be identifiable data

- Changes to BioSense
  - Map of higher resolution (county/zip) (weekly means, geospatial cluster analysis)
  - Find way to account for denominator (weighting method)
  - Works well:
    - Percentage by region available
    - Age group available
    - Some level of trend by geospatial
    - Geographic trending

Additional Notes
- To get around standard classifiers—can take raw data, reassign to fit within BioSense syndrome definition that it should be assigned to
- Develop classifier within Region 6
- Add to BioSense—add regional definitions to BioSense site (even if just posted on collaboration site)
- Data quality is a big issue
- If hospitals are sent data from health departments then the quality will go up
- Arkansas sends reports that says “this is your hospital compared to the rest of the state”
- Oklahoma—putting systems in place so hospitals can get their own data and see aggregate reports from other hospitals
- Disconnect between who’s getting the data and who’s actually interested in the data (when sending data to hospitals)

Day 2 Notes: April 9, 2014

Reflections
- What did you learn from yesterday’s experience?
- All at different stages of syndromic surveillance (diff. platforms/tools); but all looking to share information
- Better idea of challenges (data quality, political/health department infrastructure)
- Need to better understand barriers to identify solution (quality data that fits all challenges and varying definitions)
- Need to clearly delineate graphs/data (i.e., where does the denominator come from? What is the process I used to get this graph?)
  - Important for quality across jurisdictions
- Comparable summaries needed (i.e., if GI rates are going up, what does that mean? Is there comparable terminology being used?)
- Opportunity for better communication/messaging – important in change management (shift to electronic systems)
  - Standardized communication important
  - Also important to emphasize health-related benefits, **business benefits**
- Definitions for ILI vary widely → barriers to developing common classifier
- Interpretation makes a big difference in execution
- Louisiana has requirement in state sanitary code to do syndromic surveillance (part of reportable disease list for EDs)

## Activity #2

### Assumptions (basis of Activity #2 discussion)
- Limit discussion to ED visit data?
  - Yes
- Limit discussion to sharing through the BioSense 2.0 platform?
  - For people who are already signed up for BioSense—easiest to use that platform
  - For sharing, easiest to use BioSense standardized classifier
  - Keep BioSense upfront as primary mode while also thinking of ways to work around it
- Does everyone want to share data, at some level, regardless of agency readiness?
  - Yes

### Access to your data will help me to….

#### Policy
- Develop policies and procedures to improve community health
- Establish a professional relationship
- Give clear guidance to our partners (can give better feedback by knowing what’s going on on a regional basis)

#### Data quality
- Improve data quality (type of messages, text string, etc.)
- Have access to a larger dataset for analysis (more numbers)
- Compare and improve classifier sensitivity and specificity
- Improve data quality
- Work with hospital and data providers on improving data quality and reporting
- Come up with better classifier definition
- Improve own data collection methods
- Expand data elements (if collecting certain data elements, see other jurisdictions are capturing additional useful elements)
Respond
- Help other region or state
- Recommend control measures
- Be calm partners in the event of a crisis or emergency
- Improve working relationships with regional partners
- Plan and prepare for disease mitigation (if can track event, develop mitigation strategies around those events)
- Perform my job better
- Respond quickly to multi-state outbreaks
- Determine response
- Plan and respond to events
- Give better sense if we need to reallocate resources

Situational awareness
- Understand disease patterns around me
- Establish situational awareness
- Regional situational awareness depending on the format (useful report)
- Understand what is going on for situational awareness
- Identify potential health hazards that might head this way or correlate with ones we have (drug use, mental health, etc.)
- Know what’s coming
- Identify common sources of outbreaks
- Create more accurate perspective of health in our region
- See potential outbreaks headed our way
- Anticipate potential problems in our area
- Understand disease trends within my region
- Anticipate time and speed of spread of disease

Data trends outbreak/cluster identification
- Determine clusters/define clusters across borders
- See trends
- Compare health outcomes by jurisdiction
- Compare myself to others/calibrate myself against others
- Write regional report
- Compare system classifiers with other jurisdictions
- Know what’s going on in other jurisdictions
- Compare
- Compare our disease trends with other jurisdictions
- Help me compare/contrast what is going on in our localities
- Compare and understand my own data
- Baseline level of syndromic information (set expectations)
- Increase data providers (shame providers into participation)
- Understand health-related issues across jurisdictions
- Get an idea of geographic broader disease trends
• Put area in context (is something different going on here than elsewhere)
• Observe geographic spread of illness
• Understand reporting differences
• Exchange and learn and grow
• Understand geospatial trends
• In Arkansas and Oklahoma patients can opt out of having their ED data sent to public health

**Data Sharing Readiness Check**

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<th>Key</th>
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<td>All Region 6 Jurisdictions</td>
<td>CDC</td>
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<td>Vist Record (include Patient Zip Code)</td>
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Summary Note

• Once there is that compelling case, barriers seem to go away.

Next Steps by May 6, 2014

• General – develop Region 6 collaboration website on ISDS Community Forum
• GI
  o OK City will work on getting access to BioSense – Tarranat County offered to help them get connected to BioSense
  o HHS Region 6 will develop methodologies to report GI illnesses standards and classifiers
  o Work with ISDS to get a template data use sharing agreement
  o Harris County will work on getting data from Houston
  o Arkansas will be onboarding hospitals to get ED data and obtain ESSENCE
  o GI group will have email communication and at least 1 conference call to discuss methodology issues and standards
  o Houston will update data sharing agreements with hospitals to expand the language, “ability to share with public health community”
  o Hold weekly/monthly/annual calls on syndromic surveillance
  o Still not defined GI classifier to use
  o Develop recommendations for modified definition on BioSense
• ILI
  o Use BioSense as tool
  o Need to:
    ▪ Confirm data availability in some parts of Texas
    ▪ For those not in BioSense, make decisions on whether they will or won’t participate in BioSense
    ▪ Make decisions re: sharing county level
    ▪ Do some data validation
    ▪ Establish uniformed report
    ▪ Establish chain of communication

Do not share anyone else’s data without their explicit permission

Hopes for future

• Expand beyond ILI and GI in the future
• Provide broader perspective on how people treat flu in their regions
• More in-person meetings needed because communication is so important
• Share databases and protocols with each other to support data sharing
• Hope to make data sharing collaboration useful, but also easy (efficient)
• Hoping to encourage people to proceed with BioSense implementation
• Hoping for learning group (talk about challenges, how you overcome them)
• Looking forward to getting data, move forward with syndromic surveillance
• Hope to keep momentum moving