Appendix B: Workshop Notes
Introductory Activity
What was one thing you observed or learned leading up to the Workshop?

- What was the impact of 2014 northeast blizzards in flu trends?
- Difference in data provided between jurisdictions, was unsure what to expect initially but saw a wide range of data in pre-workshop activity
- Jurisdictions are at various stages of onboarding process for BioSense
- Range of ways of collecting data, types of data
- All ‘expert’ responses came from men (i.e., when asked to self-rate experience in syndromic surveillance methodologies)
- Many different ways to see syndromic surveillance
- Importance of pre-workshop work
- Where different states and locals are with development of syndromic surveillance
- Small region but very different in data collection and analysis
- So many different jurisdictions want to do the same thing but important to look for common thread
- Jurisdictions are all doing things differently, even when it falls under the umbrella of syndromic surveillance
- Saw new exclusions that might fit well in syndrome on BioSense
- Jealous of states that have people who only work on syndromic surveillance all the time
- Didn’t know other northeastern states were contributing to BioSense
- Didn’t know other flu surveillance coordinators in northeast
- Should know the people at this Workshop through syndromic surveillance work, but didn’t
- Liked hearing that other jurisdictions had problems with their data sharing bc it was reassuring to hear it wasn’t just Boston
- Cynical that data sharing can be successful
Activity #1 Debrief

Summary
- Learned a lot, responses to questions brought up new questions
- Hard to keep the focus on the data, analysis without thinking about bureaucratic barriers
- Saw potential in BioSense

Group 1 – Massachusetts, Boston, Connecticut
- What should ED visit be used/activated for?
  - When alerts are made, pay more attention to flu data
- Who must or should receive surveillance information?
  - Similar PH partners to group 2; some through listserves, others through health alerts, others make data publicly available on websites
  - Media
  - Regional partners? Weren’t mentioned!
- What other sources of data should be used and why?
  - Flu lab results
  - Don’t do school absenteeism
  - Hospital admissions (reportable condition in CT)
  - Were not using pharmaceutical data
- Commonalities
  - Saw shift in peaks between jurisdictions, but peaks looked similar
  - Age-stratified data: difficulties in finding similar trends because data differs so much
  - With BioSense classifier, could see age variations better (though BioSense classifier was not generally a good fit for data)
  - Spikes were much higher in Connecticut than in other jurisdictions
- Differences—outpatient vs. ED, 100% coverage vs. limited partnerships with data providers (geographic skewing of data), different systems, different definitions
  - Differences can also arise from how communities function at a given time (snow, school vacation times, etc.)
- Adjustments
  - People need to standardize
    - Could use own definitions AND standardized definition
  - One standard definition may not be standardizable across all jurisdictions
  - Sharing experiences, interpretations, and analyses of data
  - What is a useful regional picture?
    - What would be novel and prompt response in neighboring jurisdictions? For ILI, a lot of what people do is status quo, but regional data may be more useful in other circumstances
    - Situational awareness
Group 2 – Maine, New Hampshire, Rhode Island, Vermont

• Basic practices for I LI visits
  o What should ED visit be used/activated for?
    ▪ Monitor and report during flu season (late Sept-May)
    ▪ Continue monitoring throughout year—establish baselines, trend patterns
  o Who must or should receive surveillance information?
    ▪ Internal: surveillance and control, other health partners (immunization program)
    ▪ External: aggregate data shared with health partners (hospitals, others, general public), ME—detailed reports to hospitals that report to them
  o What other sources of data should be used and why?
    ▪ Flu lab results
    ▪ School absenteeism (from I LI)
    ▪ Sentinel I LINet
    ▪ Others that may be useful: hospital inpatient, death data, EMS runs, tamaflu prescriptions, OTC pharamaceuticals

• Pre-workshop data analysis
  o Commonalities
    ▪ Time—differed by regions
    ▪ Higher populated areas seemed to be indicative of elevated risk of I LI
    ▪ Age group peaks—0-4, 5-24, 25-49
  o Differences
    ▪ Population density could explain some spread—takes longer for flu activity to elevate in Maine
    ▪ Hospital participation
    ▪ Size of hospital
    ▪ Transportation routes plays role in spread
    ▪ Access to care
  o Adjustments?
    ▪ Using standard classifier, needs jurisdictional exclusions
    ▪ Capture jurisdictional metadata, share that
    ▪ Need to look at a lower level (lower than state-level) to make data sharing more useful

• BioSense ideas
  o Use BioSense to compare apples to apples
  o Uploading your own classifier to BioSense
    ▪ BioSense team could use those uploaded BioSense to develop a common classifier definition
  o Run query on already combined data to figure out what an ideal classifier would be
  o Boston’s data are cleaned before they go into BioSense—standard practice?
Some jurisdictions do their own data validation, not standard though
  Misspellings ARE excluded/included
  Exclusions:
    Flush
    Flutter
    Fluids
    Reflux
    Influence
    Shots
    Vaccine
    Not flu
    Not influenza
    Pregnant
  Inclusions:
    ILI
    Influenza-like
    General mis-spellings
  Spotty areas of coverage in BioSense
  Ability to use system to share information with each other, not just data
  You can send alerts even if you are not sharing data
  Need to include fever, sore throat, cough, URI, ARI, different permutations and spellings
  Instead of theoretically coming up with definitions, should send them to jurisdictions to do validation
  Making combined syndromes in BioSense would be useful
  When you combine ILI & ARI would it be de-duplicated?

- Sales could impact OTC sales
- What policy decisions are made based on the data?
  Area or age group may need targeted immunization program
  Hospital infection control practitioners may implement mask policy based on flu levels (PPE)
  Hospital-specific trends may be able to detect outbreaks that are not otherwise identified by public health
  Understanding morbidity in the state
  Situational awareness
  How well are control measures that have been put in place working?
  Need to start mobilizing anti-viral meds
  Use data on defensive—i.e., we see this trend in NY, are you seeing the same thing in CT?
Reflections

- What did you learn from yesterday’s experience?
  - A lot to learn from each other
  - Nuanced and varied approached to syndromic surveillance
  - BioSense is not a universal tool, barriers can be insurmountable
  - Other jurisdictions have limits to what data is available
  - Need for greater standardization
  - Data more comparable than expected
  - Each group has its own challenges with retrieving, cleaning, analyzing data, even before sharing data with other jurisdictions
  - Data elements differ
  - Possibility to mentor people
  - Wide variance in what syndrome definitions work well for what jurisdictions
  - There can be more than one chief complaint in a hospital system → data capture affects syndrome definitions
  - Geographical breakdown of data differs greatly (state? County? Zip code? Is it by patient address or hospital address?)

- In what ways did yesterday change your understanding of the inter-jurisdictional data sharing situation?
  - Need a mechanism to standardize data
    - Develop a representative dataset
    - Flexibility (lacking in BioSense—for instance, with modifying age groups)
      - Flexibility would also include ability to add in regional inclusions/exclusions
  - It may be more possible than originally thought—usefulness of aggregate data could be high
  - Came in with sense that BioSense was the best mechanism to share, but now not sure that’s the best sharing mechanism
  - BioSense has the potential but there are a lot of challenges along the way
  - Don’t necessarily have to conform to what everyone else is doing, can shape what the mold will be
  - Can learn from what’s been done already
  - Can share techniques, mentor, share ideas
  - See group as community of practice
  - Look into Providence Plan—have lots of health data
  - A lot of value to sharing observations, discussions, processes with other jurisdictions
  - Enhanced event-based functionality → could be similar to Epi-X but less controlled
Activity #2

Assumptions (basis of Activity #2 discussion)

- Limit discussion:
  - Should it be limited to just ED data?
    - Data sharing could also be disease or problem-specific
    - For the purposes of this discussion, yes
    - Don’t limit conversation to just ILI
      - ILI
      - GI
      - Lyme disease
      - Arboviruses
        - Data is already shared broadly, but not together in a single, aggregated place
      - Vaccine preventable diseases
        - Measles
      - Case-specific (e.g., local heroin overdoses, serious winter weather, CO exposures)
      - Boston and New Hampshire both did analyses on opioids but Boston did not split it up directly into heroin (Boston couldn’t use chief complaint bc they were useless→ used ICD-9 codes)
      - Some departments get pushback if they try to get out of the realm of infectious diseases
        - Can not do “data mining”, need to be formally requested
  - Where is the value in this data if you can’t explore it, define where the value is after you have the data
    - Depends on conversation—for vaccine-preventable would want lab data, vaccination rates, etc.
    - What’s added value in running syndromic surveillance on reportable diseases—pre-diagnostic and can be used for things like flu which is reportable in some states but not others
    - Notifiable diseases—can be difficult to capture by symptoms (but sometimes disease name may be listed in chief complaint (e.g., with chicken pox))
    - Incorporated exposure into daily reports (NH)
    - Boston has a syndrome that looks for disease terms (e.g., in chief complaint field—sometimes helpful, sometimes not; also have been notified about outbreak of Kawasaki’s from providers, looked at ICD-9 codes and saw visible spike in data)
    - Final answer: yes, source we all have in common, can be a good starting point BUT down the road will likely want to share other
types of data too (do not want to be myopic in view of information and practice exchange)

o Should it be limited to just BioSense?
  ▪ No—why?
    • Not there yet
    • Functionality gaps
    • Could share information but not place to go to analyze data
    • Need workflow support and data sharing support
  ▪ Yes—why?
    • Could be a useful anchor point for data sharing
    • Since BioSense is platform for data sharing it’s a good place to start the conversation
  ▪ What about people who may have access to BioSense but do not currently have any data in BioSense?
    ▪ FINAL ANSWER: YES, use as jumping off point
  o Does everyone want to share data, regardless of their readiness?
  ▪ Individual (line-level)
    • No – Everyone
  ▪ Aggregate (dataset) \(\Rightarrow\) depends on denominator
    • Yes—but, depends on privacy laws (qualifier for all yes responses)
    • Yes – NH, Boston, MA, ME, RI, VT
    • Maybe – Connecticut (could share analyses but not datasets)

**Barriers to data sharing**

_____ is a barrier to the data and surveillance information sharing we discussed (i.e., ED visit) – participants were asked to fill in the blank

- IT at participating hospitals
- Personality
- Lack of experience
- Time (competing priorities)
- Legal department
- Confidentiality and privacy
- Differences in syndrome definitions
- Difficulties with HIE
- Differences in data validation and collection
- Effort
- Lack of motivation (self)
- Time constraints
- Current system \(\Rightarrow\) legacy constraints
- BioSense \(\Rightarrow\) not being allowed to participate \(\Rightarrow\) if others are using BioSense to share data can be a problem
- Technology needed to move things forward
- Funding to support effort and tools
- Leadership support (lack of) → from state epi up
- Policies in terms of what can and can not be shared (both laws and personalities)
- Differences in analyses between jurisdictions
- Data quality
- Define minimum standards
- Technology
- Data use agreements → ensure contracts with hospitals include clause that data can be released (hospital to public health agency)
- Data cleaned vs. not cleaned before submitted (lack of standard for data cleaning)
- Lack of will
- Different systems being utilized
- Hospital compliance
- Confusion and misunderstanding of legal issues
- Day to day response
- Personalities—those who think they own the data
- Ability to think outside the box → close mindedness
- Messy data (raw data from hospitals)
- Staffing (no single person on syndromic surveillance, look at data on an ad hoc basis)
- Technical barriers
- Electronic transmission issues
- Different data elements are generated
- Specifics regarding the data elements
- Habits of major actors
- Bad past experiences → try to share once get slapped down, why try it again?
- Bureaucracy—what level do you need to work at to implement change?
- Have to work through chain of command
  - Groupings:
    - Legal/privacy concerns
    - Personal
    - Resources
    - Tools
    - Data standards and quality
    - Organizational culture
- #1 barrier to tackle (think you can tackle)
  - Legal/privacy
  - 2- Tools
  - 3-Personal
  - 4- Data standards and quality
Solutions to barriers

- Process engagement alone will increase motivation
- Share, compare and contrast syndrome algorithms by ICD-9 and chief complaint data to see similarities and differences (ILI-specific)
  - Use that information to arrive at consensus on acceptable level of standardization
- Each state cleans their data differently so compare systems for cleaning data between jurisdictions
  - Talking about how each state does it differently (some clean data ahead of time, others account for misspellings in syndrome definition)
- Create community of practice
  - Forum
  - Phone call with screen share
  - Develop concrete actions and tasks not just discussion
- Data standards/quality
  - Create metadata document
  - Develop standard classifiers
  - Documentation of issues with data
- Personal
  - Standard would not be enforced (i.e., if you can’t meet the standard it doesn’t mean you’re kicked out of the group)
- If don’t validate data in same way it may not be applicable
- Distribute
  - Saw need for standard classifier/working towards standard classifier

• Developed process to address personal issues, process will help address data standards and quality issues

Next Steps by March 17, 2014

- Create space for discussing this further
  - Follow-up call scheduled for March 17th; discuss then need for additional sharing modalities
- ISDS: Provide compiled information, identify gaps
  - Spreadsheet compiling → responses to questions
  - Provide narrative to accompany data—what do you do with it, what are the issues?
    - What is your syndrome definition that you use in-house?
      - Copy and paste algorithm you use → compare and contrast algorithm details
      - Exclusions and inclusions only
      - Akshar will compile this by 3/17—send him information
- ISDS—invite everyone to google drive folder (with their email addresses)