September 12, 2013

The BioSense Governance Group
c/o Scott Gordon, PhD
Association of State and Territorial Health Officials
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Re: Recommendations for improving BioSense’s data sharing capability

Dear BioSense 2.0 Governance Group:

The following letter is intended to establish a dialogue between surveillance professionals and the BioSense Governance Group. We are interested in establishing data sharing relationships across jurisdictions utilizing BioSense. Within this letter are a number of recommendations for increasing the feasibility of this data sharing process in BioSense. Recommendations include: 1) increased documentation and additional tools; and 2) functionalities in the BioSense application. In addition, we request a continued conversation with the BioSense Governance Group and a forum through which to address these and future recommendations.

On May 20-21, 2013, the International Society for Disease Surveillance (ISDS), with the support of the Association of State and Territorial Health Officials (ASTHO), convened a Workshop of jurisdictions (ISDS Data Sharing Workshop), mainly from Region 5 of the Department of Health and Human Services (HHS). The two-day Workshop brought public health professionals working in syndromic surveillance together to discuss their current syndromic surveillance systems and practice, as well as their desire to share data between jurisdictions. As part of the Workshop process, data sharing was enabled between all participating jurisdictions, which helped to facilitate conversations and identify steps we need to take to establish long-term sharing of syndromic surveillance information. Workshop participants came from the following jurisdictions:

- Illinois Department of Public Health
- Cook County Department of Public Health
- Chicago Department of Health
- Wisconsin Department of Health Services
- Michigan Department of Community Health
- Indiana State Department of Health
- Marion County Public Health Department
- Ohio Department of Health
- New Hampshire Department of Health and Human Service
During the Workshop, we identified several vital public health activities that would benefit from greater syndromic surveillance data sharing among participating jurisdictions. BioSense can be an important tool in building the capacity of public health agencies to share data in near real-time. In particular, data sharing through BioSense can aid our jurisdictions in:

- Cross-border case-finding
- Identifying patterns or trends (local, state, regional, federal)
- Emergency preparedness planning and partner notification
- Mutual aid
- Making sure federal government has complete picture
- Hypothesis generation and testing

In its current state, however, we find that there are resource and functionality gaps that limit our ability to share data within BioSense.

To share some insights gleaned prior to, during, and after the Workshop we present the following as examples of how BioSense could be modified and improved. Incorporating these recommended functionalities and tools will allow our jurisdictions to effectively utilize BioSense for the above syndromic surveillance data sharing.

The following two (2) items are of the highest priority to Workshop participants:

1. A user guide that provides practical guidance for using BioSense in practice (including both individually and if data sharing is enabled)
   a. Including a description of BioSense algorithms (i.e., how is data binned?)
2. Greater and more granular control over what data is shared with whom
   - Jurisdictions should be notified of any Data Use Agreement (DUA) changes in shared data
   - User level stratification would be useful (e.g., group people as public health practitioners, researchers, etc.; allow users to grant control to any or all of these groups individually)
   - Would like control over granting permission to individual counties within a state (e.g., allow users to grant permission to one county within a state but not all)
   - Ability to assign different levels of access to different users within a jurisdiction
Documentation on the following details is also of high priority to Workshop participants:

- **Documentation that describes the process or procedure by which records are binned and made available for analysis using the front-end BioSense application**
  - Consider posting on Community Forum or similar platform, BioSense application site, or similar platform
  - Would ideally like the ability to look at data pre-binning
- **Documentation (via tooltip) on:**
  - User management control panel
  - Data sharing control panels
  - Line-level export
- **Documentation of metadata, including the description of specific sources that are reporting data (e.g., is it emergency department data only? What are the normal number of ED visits in a day? What proportion of the jurisdictional population is covered?)**
- **Documentation of data quality metrics on the front end, particularly high-level metrics such as completeness of data, percentage of categories captured, etc.**
  - It would be useful to include automated data quality checks—for example, if age data is sent to Biosense but is not showing up on the backend, it should trigger an alert.
  - There needs to be a way to assess the quality of a jurisdiction’s data before including it in shared analysis.
- **Documentation of how RTI is responding to user needs to increase transparency and enable an open dialogue between users and RTI**
- **Documentation of syndrome definitions utilized in BioSense**
  - Including a complete description of inclusion criteria for each BioSense syndrome

Finally, the following tools and functionalities would be beneficial to increasing individual jurisdictional use as well as data sharing through BioSense:

- **Additional data visualization options, including the ability to see the following:**
  - Trends over time in the number of hospitals
  - Trends over time for total report volume
- **Allow users to identify quickly and easily with whom they are sharing data (written documentation requested)**
  - For instance, if a user is sharing data with a state, who within the state can see the data?
- **Permit users to specify information about their data**
  - Individual jurisdictions know their data best. In order to allow other jurisdictions to effectively use their data, it would be useful to have a
short document describing the jurisdictional data and any nuances that may be vital to data interpretation.

- **Feature release notes on incremental changes and fixes**
- **Ability to customize syndromes, including the following:**
  - Ability to use exclusion terms in searching chief complaints
  - Selective sharing by syndrome instead of all data
  - Ability to add custom search terms, including ability to choose what terms to perform a query on (chief complaint, diagnosis code)
  - Delineation of heat exhaustion in the syndrome definition—ICD codes 992.5, 992.6
  - Stratification of classifiers (chief complaint, diagnosis code)
- **Increased data visualization capability**
  - Ability to split compare graphs—tab through graphs, make the data easier to view on one interface
  - Greater granularity of geographic data down to the 5-digit Zip Code level
  - The ability to select and view data from individual sending facilities within a jurisdiction
- **Establish model policies/standard public health practices around protection of confidentiality, with a focus on legal barriers**
  - Could include a standardized DUA for BioSense users

Thank you for taking the time to consider our comments and suggestions. With the recommended modifications, BioSense could become a fully integrated data sharing mechanism that would more effectively benefit syndromic surveillance practice throughout our region.

If you have questions about any of these items, or would like to schedule a follow-up call, please contact Charlie Ishikawa at 617-779-0886 or cishikawa@syndromic.org.

Sincerely,
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