Background

The second annual National Syndromic Surveillance Program (NSSP) grantee¹ meeting was held February 6–8, 2017, in Atlanta, Georgia. One session consisted of a series of roundtables in which meeting attendees participated in facilitator-guided discussion on four key areas of syndromic surveillance:

1. Data quality,
2. Data sharing,
3. Data representativeness, and
4. Syndromic surveillance practice.

The overall session was organized so that two concurrent roundtable discussions occurred during the first half of the session and two in the second half, enabling four roundtable discussions on the four topic areas. Each 50-minute session was facilitated by one Centers for Disease Control and Prevention (CDC) project officer and one site² representative. Participants were free to choose the issues discussed at each roundtable that pertained to the respective topic area for discussion. A notetaker from CDC was present at each roundtable to capture the discussion. This report presents findings from a qualitative analysis of the notes collected by the notetakers.

¹ Grantee refers to the entity that receives funding through its cooperative agreement with CDC.
² NSSP consolidates facilities that provide data under a single data administrative authority called a site administrator. These facilities and single-site administrator constitute a site.
Methods

This analysis was conducted by the program evaluation team and based on notes taken at each roundtable by staff of the Division of Health Informatics and Surveillance (DHIS). Notes were coded and analyzed after the conclusion of the grantees’ meeting.

Thematic analysis techniques were used, and the findings are highlighted in this qualitative report. Sites (including states and counties) are not identified by name. Theme frequencies are provided in parenthesis with a brief description of each theme. Frequencies are purely for general information and do not indicate relative importance.

Analysis was conducted with MAXQDA 12. The codebook is available upon request.
Results

Data Quality

Three aspects of data quality were discussed during the session. Participants from the various sites noted particular issues they face in improving data quality. They also mentioned factors for why improving data quality was a challenge and provided strategies they use to overcome these issues.

Data quality concerns (3)

One site noted challenges in improving data completeness and that getting vendors to use standardized value sets is an issue faced regularly.

Another site noted difficulties getting timely data from certain vendors, hindering the site’s ability to move these facilities into the production environment. This site noted that one vendor batches and sends data from several facilities at the same time, leading to file sizes that are too large to ingest.

One site had issues using both SQL and R for data quality analyses and that assistance on this topic would be beneficial. Another site noted the need for a data quality database that could be used to run a variety of reports.

Challenges in improving data quality (7)

Site participants noted many reasons for the difficulties in assessing data quality within their systems. One site noted that many issues stem from business processes specific to individual facilities. Such processes cause the health department to have difficulties ingesting data and, due to the independent nature of these facilities, are difficult to change.

Several sites noted they often have difficulty illustrating the need for improved data quality. In their discussions with vendors and facilities, they are unable to provide clear examples of why particular elements are important to collect. One site noted that vendors that are satisfied with the current data feeds see no need to improve the data they send. Even when health department staff contact these vendors, their response rates drop dramatically and progress is difficult to achieve.

Still another site noted difficulties in improving data quality when facilities change vendors regularly. This site gave an example of one facility that had changed electronic health record (EHR) vendors five times.
Strategies to address data quality issues (5)

One site noted its process for examining data feed quality and how it is based on pulling chunks of data for a time range and exploring the value ranges for variables of interest and for completeness. This data checking was mainly done through SQL. However, the site expressed interest in comparing in-house data quality reports with CDC’s data, including the results and processes for developing these reports.

One site noted that the healthcare facility has a role in managing vendors and providing sites with the data needed. This was suggested as another way to promote data quality improvements among nonresponsive vendors.

Participants belonging to a couple different sites noted their limited power to affect change. They suggested that federal agencies such as CDC or the Office of the National Coordinator for Health Information Technology (ONC) could engage with vendors and facilities that are not meeting data quality standards. They suggested another way to address data quality issues was greater coordination among sites, which would allow for collective action.

Data Sharing

Three themes emerged from the data-sharing discussion: variety of data-sharing agreements used by sites; issues that decrease data-sharing opportunities, both within and among sites; and ways to improve the ability of sites to share data and syndromic surveillance tools more broadly.

Variety of data-sharing agreements (8)

Sites noted a wide range of data-sharing agreements:

- One site noted a time-limited data-sharing agreement with another site, which served as a great way to set the stage for future collaborations.
- Another site noted having a data-sharing agreement at the regional level for influenza-like illness (ILI) data. This agreement allowed a nongrantee to gain access to critical ILI data.
- One site’s data-sharing agreement allows its system users to see data from two neighboring public health jurisdictions. In return, the site provides weekly reports on queries to the neighboring public health jurisdictions. This has led to constructive use of syndromic surveillance data for opioid control efforts in neighboring public health jurisdictions.
In addition, NSSP sites are beginning to share data with a wide range of partners within and outside their respective health departments. For example, several sites share data with programs related to opioids; and another site shares data with a smoking cessation program. A few sites have staff who have met with suicide and chronic disease prevention groups about gaining intrasite access to syndromic surveillance data.

Barriers to increased data sharing (7)

Sites noted having difficulties with data-sharing processes and agreements:

- One site noted difficulties in establishing data-sharing agreements with a neighboring site due to concerns about data ownership. State hospitals in the neighboring site consider facility-level visit numbers to be proprietary. To resolve this issue and respond to these sensitivities, the site developed aggregate data groups or “super-counties.”
- One site noted that parts of the state are so rural that facilities become identifiable if they are not aggregated. This limits data sharing within the site.
- One site noted that laws can restrict data sharing. Its state laws on sharing data are unclear, which makes the site hesitant to add new data sources or to increase data sharing among counties. This lack of clarity often stifles public health departments from building highly collaborative and functional relationships.
- A participant from another site mentioned a need to revise the data-use agreements to allow for follow-up with a hospital about data received.
- Health Insurance Portability and Accountability Act, or HIPAA, compliance was mentioned by a one site as a tool used by hospital staff to limit record-level data sharing. In response to this issue, however, one site noted that syndromes were made reportable to address HIPAA restrictions-related matters.

Strategy considerations and tools to increase data sharing (5)

The participants were interested in innovative ways to share data among sites.

- One site noted the creation of a new “site” that crosses borders and allows for sharing record-level data. However, two other sites wanted to create a different data-sharing arrangement that was not compatible with the current environment (BioSense Platform functionality). An example of this would be where one site wants to share data with all registered syndromic surveillance users from another site. This led one site to note that comprehensive documentation on the capabilities of the Platform would be beneficial. Working
with sites to determine the viability of these arrangements, and potential solutions to limitations, will be essential as data sharing continues to increase.

- **Participants from several sites expressed the need for some sort of a knowledge repository around data sharing.** They thought this would be especially useful for low-resource sites.
- Another site noted that a shared dashboard could be created to serve as a template for future outbreaks or other events.
- One site wanted to know whether queries could be shared without the underlying data. This was another item that could be added to any future knowledge repository.

### Data Representativeness

Discussion during the data representativeness and recruitment roundtable session was wide ranging. Participants discussed representativeness from the perspective of facilities, geography, and subpopulations. They also noted issues around the onboarding of outpatient facilities and standalone emergency departments.

#### Subpopulations (6)

- Sites noted gaps in particular subpopulations that they are trying to focus on.
  - One site is trying to onboard a children’s hospital because one of the first questions asked during an outbreak is whether children are being affected. Currently, this site has **limited insight into the health of the child population**.
  - Another site noted its efforts to collect **data from school nurses**. These data have improved reporting of key health concerns such as asthma and diabetes for underserved populations. The collection of data from school nurses stemmed from an effort to incorporate school absenteeism data into syndromic surveillance, and the added value was found to be even higher than estimated. Data provided by school nurses presents a better overall picture of youth health.

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3 The data analysts were not provided with specific suggestions. “Knowledge repository” might refer to the sharing of best practices, system documentation, etc., which can significantly help low-resourced states. NSSP will follow up.

4 Per Coates et al., data representativeness refers to the syndromic system’s ability to “accurate describe the occurrence of health-related events over time and their distribution in the population by person and place.” For a thorough discussion, see the following article: Coates R, Pérez A, Baer A, Zhou H, English R, Coletta M, Dey A. National and regional representativeness of hospital emergency department visit data in the National Syndromic Surveillance Program, United States, 2014. *Disaster Medicine and Public Health Preparedness*. 2016;10(4):562–9.
One site noted its attempts to get data from critical access hospitals, which are not required to send syndromic data or attest for meaningful use.

The same site also noted the gap between population-based and geographic representativeness. Most of its population is well represented in the syndromic surveillance systems, but more must be done to provide outreach and support to small community hospitals in rural settings.

Emerging issues with outpatient and standalone emergency facilities (6)

The health provider landscape is rapidly changing, which affects sites working to onboard facilities.

- Several sites noted an increase in standalone emergency facilities that are sometimes associated with a hospital network. In some states, issues arise because these hospital-associated standalone facilities do not have their own data feeds, making it difficult to distinguish between data from the hospital and data from the standalone facility. Two sites noted that jurisdictional law states that stand-alone facilities need to be associated with a hospital.
- Outpatient facilities are another emerging class of healthcare facilities with which sites are beginning to work. However, one site noted that although these facilities are used by a large portion of the population, the focus needs to remain on traditional emergency room data. Another site noted that they work with some outpatient facilities but that getting data on follow-up visits was a challenge.

 Syndromic Surveillance Practice

Discussion on syndromic surveillance practice focused on three key themes. One was about the various issues encountered in the everyday use of syndromic surveillance data—from the types of events and diseases being monitored to site-specific workflows (i.e., in-house reporting, investigation, and follow-up protocols; state and federal reportable conditions). Participants from the various sites also noted barriers to the increased use of syndromic data within their public health jurisdictions. Finally, they discussed the future of syndromic surveillance in the context of policies affecting use, strategies for increasing data use, and areas for future development.

 Syndromic surveillance data use and practices (13)

Sites noted a wide range of uses for syndromic surveillance data. One site uses syndromic data for reportable disease surveillance. However, most other mentions of
data use from other sites focused on syndromic surveillance data for events that are not typically covered by traditional surveillance such as drug overdose, weather-related events, and even community health assessments.

Participants from different sites discussed their typical workflow response to alerts generated by their systems. For communicable diseases, alerts are typically sent to public health nurses or disease subject matter experts (SMEs) for further exploration. One site noted that it compares communicable disease alerts with the National Electronic Disease Surveillance System (NEDSS)—so those alerts already showing in the system are closed out, and those that have not been reported are then shared with a disease SME for follow-up. Noncommunicable disease alerts were usually communicated to facilities, local epidemiologists, or local health departments by using an automatic email alert system.

Barriers to syndromic data use (14)

Participants noted many barriers to the broad use of syndromic surveillance within their sites. Some health departments that work with sites resist the use of syndromic data because their existing systems already capture these data. Sites noted that epidemiologists usually work with systems with which they are familiar.

Syndromic surveillance’s role in the public health infrastructure remains somewhat unclear to many sites. Some sites note that despite their electronic health record, or EHR, system being advanced, some epidemiologists are unsure about the added value of the use case for syndromic surveillance to these new information technology systems. Sites that despite being acknowledged experts in ESSENCE and syndromic surveillance note that they are not considered disease experts—which leaves their role in the disease control workflow unclear.

Determining procedures for how to handle alerts is an area where sites see the need for further development. For example, when a site gets alerts for certain syndromes of high importance but low likelihood of being a true case, how do they best handle the communications that need to occur to make sure the alert is resolved without overburdening the public health system? This raised the larger issue of communicating effectively about the nuances of syndromic surveillance data. Many public health practitioners are unaware of the variable nature of syndromic surveillance data. This leads to uncertainty among sites about how to communicate information to avoid having it wrongly interpreted by someone unfamiliar with the data.
Successes and future areas of development (11)

Despite the challenges noted, sites provided numerous strategies for increasing the use of syndromic surveillance data. They mentioned the need to go outside the communicable disease box. They are now considering how syndromic surveillance data can add value to other areas such as injury prevention and emergency preparedness. Increased communication with these programs helps as does providing them with interesting products (weekly syndrome reports, situational awareness reports in emergencies) that keep them coming back when questions arise. One site noted that it has found great value in the use of syndromic surveillance to rule out noncases of disease.

The participants acknowledged that more could be done to synergize the field of syndromic surveillance. They mentioned community development of queries and greater standardization of syndrome definitions. Efforts in these areas are already underway for opioid surveillance. One site noted the Syndromic Surveillance Community of Practice is a crucial component that builds stronger syndromic surveillance practice through its use of working groups, forums, and resource and knowledge repositories.

Participants noted that meaningful use, overall, has helped sites in the National Syndromic Surveillance Program achieve improved health data flow. This trend should continue to advance syndromic surveillance.
Conclusion

In these wide-ranging roundtables, the participants noted several ways in which they have improved data quality. They described practices for checking data quality issues and the roles of various stakeholders in this process including facilities, vendors, health departments, and federal government. Data-sharing agreements are being developed all the time; however, certain barriers remain, including external factors such as ambiguous legislation and internal limitations such as the current data-flow infrastructure. Providing guidance on these various issues around syndromic data sharing will allow sites to further expand their data-sharing relationships. As facilities such as standalone emergency rooms become more prevalent, sites are adjusting their onboarding procedures to fit the new healthcare landscape. These changes affect recruitment and maintenance of facility data feeds and will require vigilance on part of the sites and CDC. Syndromic surveillance programs face challenging environments within their geographic jurisdictions. On the one hand, the sites are experiencing reluctance on the part of disease programs to use these “new” data. Other sites fear the misinterpretation of syndromic data among those who are eager to use these data but are unaware of its nuances. As sites build stronger, more trusting relationships within their health departments, they will need support in educating public health practitioners about how to use syndromic surveillance data correctly.

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