

## Appendix C: Phase I Summary Report

# State Health Department Access to Electronic Health Record Data during an Outbreak: A Retrospective Assessment Preliminary Summary Report

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## Introduction

Two years ago, contaminated steroid injections caused the largest fungal meningitis outbreak in the United States, affecting 20 states and resulting in 751 infections and 64 deaths. The subsequent healthcare-associated infection (HAI) outbreak response required significant collaboration between healthcare providers and facilities and public health departments (HDs). Following the outbreak response, HDs reported that various challenges with access to patient health information in electronic health records (EHRs) hindered the efficient and rapid identification of potential fungal meningitis cases in healthcare facilities. The fungal meningitis outbreak experience highlights the need to better address the landscape of granting and using access to EHRs for outbreak investigations.

The Division of Healthcare Quality Promotion, the Office for State, Tribal, Local, and Territorial Support, and the Office of Public Health Scientific Services at the Centers for Disease Control and Prevention (CDC) are partnering with Association of State and Territorial Health Officials and The Keystone Center to evaluate the challenges surrounding HDs access to EHRs in healthcare facilities' during an HAI outbreak investigation. The evaluation seeks to compile information across states from experts in the public and private sector to assess experiences, identify issues, and seek recommendations for improving HDs access to EHRs during public health investigations.

In addition to an assessment report, the results from healthcare facility staff will be used to build a toolkit to help state HDs address the needs of the healthcare facilities related to EHR access. The toolkit will provide perceived barriers, recommendations to overcome those barriers, best practices that support EHR access, and practical tools such as templates, memorandums of understanding (MOUs), and policies. The toolkit will be distributed to HDs, healthcare facilities, and other stakeholders to support awareness and strengthen relationships between public health and clinical care. These activities will facilitate the quick and efficient identification of cases in outbreaks and protect the health and safety of patients.

## Methods

We conducted 45 phone interviews with 52 state health officials in 12 states as described below.

1. **State Health Officials.** We requested participation from 55 public health department employees and successfully completed 45 phone interviews with 52 state health officials', an 80% response rate, in the

following roles: healthcare associated infection (HAI) coordinator (n=14), epidemiologist (n=15), legal counsel (n=6), and informatics director (n=17).

2. **State Sample.** Data was collected from state health officials' in their official capacity in the following 12 states: Florida, Indiana, Kansas, Maryland, Michigan, Minnesota, New Hampshire, New York, Oregon, Tennessee, Texas, and Virginia. These states were chosen based on four criteria: 1) case count during the fungal meningitis outbreak; 2) experience with other outbreaks, 3) existing state or local laws related to EHRs, and 4) demonstrated leadership in EHR and health information exchange (HIE) implementation. Interview guides were developed for three roles, one clinically-oriented, one legally-oriented, and one oriented towards information technology.
3. **Phone Interviews.** Data were collected using telephone interviews. Interviews were conducted using interview guides specific to the role of the interviewee (including HAI coordinators, state epidemiologists, state legal counsel, and informatics director.) Two CDC employees tested all the interview guides with state health department employees experienced in the topic of the interview. Feedback was used to refine questions and probes and estimate burden hours. In all three interview guides, there are six overarching questions:
  - A. What is your official title?
  - B. What has been your experience with the health department requesting and/or getting access to electronic health records from clinical providers in your jurisdiction?
  - C. How do you define electronic health record access in your jurisdiction?
  - D. What were some of the barriers [real or perceived] you experienced or heard about to help address requesting and/or getting electronic health record access?
  - E. What are the greatest lessons that you learned when requesting and/or getting electronic health record access?
  - F. What would you like to see in the toolkit that could help us to address health departments' access to electronic health records?

The interview guides assist in the comparative analysis of findings, with six overarching questions and related probes that focus questions to the role interviewed. The probes, specific to the role interviewed, serve as a guide for the interviewer should they need support and to ensure all project objectives are being collected; therefore, not all of the probes were used in every interview.

## Preliminary Findings

Data Collection concluded at the end of August 2014. Although data analysis is ongoing, preliminary findings can be grouped into seven major themes:

1. **EHR Access.** All participants had the ability to access EHRs in healthcare facilities, including hospitals and clinics, in their jurisdiction. However, the type of information needed, when information could be accessed varied greatly. While some HDs could access the entire EHR through the system, other HDs

could only access portions of the records within the EHR system, limiting their ability to access and find the information they needed. EHRs were primarily accessed by HDs on-site at healthcare facilities. In many cases the HD had to drive from facility to facility on a regular basis to locate cases, spending time and resources that were very valuable during the outbreak response. There were some instances where the HD had remote access, or the ability to access a network of healthcare facilities from one location, and few instances where the EHR could be accessed from the HDs office. While the HAI fungal meningitis outbreak necessitated that HDs access healthcare facility EHRs, it was the first time that many HDs requested and gained that access.

2. **Authority.** There were no instances where the healthcare facility questioned the HDs authority to access EHRs. Although state laws vary in the authority granted to HDs, federal and state laws served to facilitate the HDs' ability to gain access EHRs.
3. **Capacity.** EHR systems varied greatly among healthcare facilities. First, while most hospitals did have an EHR, many clinics did not. As previously mentioned, most EHR access was conducted on-site at the healthcare facility, potentially resulting in fewer technical issues than if access was remote. Second, the ability to locate and use the information in the EHR was a significant challenge for HDs. Healthcare facilities' used a number of different EHR systems, but even the same system was configured in specific ways for their unique needs, which significantly changed the look and feel of the EHR, as well as the ability to find information. Third, in most cases the EHR did not have the ability to export information; therefore, HDs had to create their own databases and manually pull pertinent information from EHRs. Finally, most HDs did not have the ability to query, or search, the EHR system for a set of symptoms or treatments because most healthcare facility staff did not know how to use their EHR system in that way or if it was even capable of being queried. These realities made case identification more challenging, and in many instances, HDs were left to rely on individual staff members to relay information about potential cases.
4. **Relationships.** Relationships between healthcare facilities and HDs proved to be crucial to facilitating the outbreak response. Because of the urgent health concerns related to fungal meningitis, HDs were requesting immediate EHR access. HDs that had existing relationships with healthcare facilities encountered fewer barriers and were able to develop agreements to access EHRs more quickly as compared to those who were forming relationships for the first time.
5. **Sustainability.** Contractual agreements created during the outbreak were often made in rapid fashion without thought to future outbreaks, and the applicability and sustainability of the agreements were not considered. Many agreements have expired and many HDs have not renewed them across facilities due to limited resources. For this reason, many HDs would have to rebuild relationships and create new agreements in the context of a new outbreak.
6. **Security.** Perceptions related to data security were more of a bump in the road, rather than a barrier. Because access was primarily onsite at healthcare facilities, there were few security concerns related to remote access. HDs mainly encountered security concerns while getting login and passwords to access EHRs, which may have caused delays for a few days. Those HDs who had developed relationships with healthcare facilities received access to the EHR system more quickly, compared to those who were forging new relationships.

7. **Privacy.** Perceptions of privacy laws were an initial barrier for HDs to gaining access to EHRs in healthcare facilities. During the fungal meningitis outbreak, many healthcare facilities and HDs lacked uniform understanding of the guidance federal and state laws provide related to patient privacy and EHRs, particularly related to the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Requests for EHR access gave many healthcare facilities pause, but in most cases, a conversation between the HD and healthcare facilities' legal counsel about the exceptions for HDs under HIPAA easily resolved this issue.

## Application of Findings

In addition to an assessment report, the information from this assessment will be compiled in a toolkit to help state HDs address the needs of the healthcare facilities related to EHR access. The toolkit will provide perceived barriers, recommendations to overcome those barriers, best practices that support EHR access, and practical tools such as templates, memorandums of understanding (MOUs), and policies. The report and toolkit will be developed into a website that will be housed on the Association of State and Territorial Health Officials (ASTHO) website, with links posted on the Centers for Disease Control and Prevention's HAI website. Emails will be distributed to states to share the information in effort to support awareness of best practices, barriers, and policies. The toolkit will be distributed to HDs, healthcare facilities, and other stakeholders to support awareness and strengthen relationships between public health and clinical care. These activities will facilitate the quick and efficient identification of cases in outbreaks and protect the health and safety of patients.