



A Tale of Two Agencies: The Quest for Developing a Health Data Sharing Agreement

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Introduction

Hospital data plays an important role in public health surveillance. In Florida, hospitals and medical care facilities are required by Florida Statutes to report patient health data to the Agency for Health Care Administration. Throughout time, the Florida Department of Health (FDOH), Office of Planning, Evaluation, Data Analysis and Statistics (Vital Stats) has been the primary users of AHCA data to cross verify vital birth and death records. AHCA provides non-confidential health data to the Office of Vital Stats on an annual basis.

Currently, FDOH is being funded by CDC to help develop an environmental public health tracking network (EPHTN). One of the primary goals of EPHTN project is to link selected hospital health data with data on environmental hazards, to help identify patterns and trends of chronic diseases in the population. For example, linking asthma hospitalization data with outdoor air pollution data to identify if there are certain times of the year when there is an increase in rates. Obtaining confidential hospital data on an on-going, un-interrupted, electronic basis is crucial for the project to succeed.

AHCA has an annual renewal application process for confidential information that has been both cumbersome and time consuming to complete. As a "sister" agency, FDOH is still required to complete many application forms, obtain multiple signatures, and proceed through a lengthy, often time-delayed process of obtaining recurring data.

A request for confidential information to AHCA, from any state agency, Division or Bureau within government, requires the applicant to complete a formal application, and a hierarchy of upper management signatures from both Agencies. Despite the importance of obtaining data from AHCA, there has never been an "official" agreement between the two agencies that would allow Division's, Bureau's at FDOH to obtain confidential data in an easy manner.

Currently, health and environmental data is stored and under utilized for the purposes of environmental public health surveillance. It is unknown, but hopeful by the author, that state environmental and health agencies will seek a more permanent change for the ability to share data in the near future. At the national level, the US EPA, is making a paradigm shift to share data with other agencies in an attempt to increase accountability. It is hopeful that others will follow suit.

Problem Statement

In Florida, the Agency for Health Care Administration (AHCA) requires the Florida Dept. of Health (FDOH) to proceed through a lengthy and time consuming application process to receive health data. As a "sister" governmental agency, bound by similar health care protection laws and regulations as AHCA, FDOH receives no special consideration or expedited review in the data request process. This process presents concerns for surveillance purposes. This process appears to be similar at the national level, and needs to be streamlined, so that health data can be more easily retrieved by state (environmental) health departments.

Materials and methods

Event: Awareness of issue is common knowledge among key stakeholders and upper management.

Activities:

- Internal FDOH meeting held to discuss strategy to move towards developing a Data Sharing Agreement.
- Obtain an electronic spreadsheet list of all FDOH users of AHCA data.
- Hold internal FDOH meeting. Appoint liaison, Meade Grigg, Director, Office of Planning, Evaluation, Data Analysis and Statistics, to take leadership role to discuss a data sharing agreement with AHCA.
- Meeting scheduled with new leadership at AHCA to develop DSA.

Results

At this time, a formal DSA between FDOH and AHCA has not been developed, however an interagency data application (see Figure 1) was modified to help ease the data application process. The interagency request for data is now a less intensive process, however, still requires an annual renewal. Additionally, a recent change of leadership has prompted another meeting which may prove to be an opportunity for securing a DSA in the near future. In addition, communication between the two agencies has increased, and the stimulation provided by this project has helped to formulate an internal partnership among selected Division's within FDOH, and gain momentum to support an effort for a DSA.

Figure 1



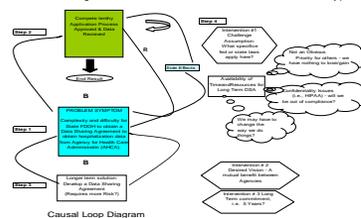
Figure 2



As shown in Figure 2, the Behavior Model illustrates the Department of Health's desire to share health data with AHCA continues to increase overtime. (This was measured by the increase in the number of data requests to AHCA by FDOH). The Division of Environmental Health made substantial progress in 2005, by entering into an agreement that would allow FDOH to receive data electronically (via ftp). Since that time, discussions have continued to develop a DSA, however, little progress has been made.

Figure 3

Shifting the Burden and Fixes that Backfire - Archetypes



As shown in Figure 3, the Shifting the Burden and Fixes that Backfire archetypes were used to illustrate the problem symptom of obtaining a DSA. The reinforcing loops illustrate unintended consequences that compound the problem.

10 Essential Environmental Health Services:



Figure 4

As outlined in Figure 4, this project, meets six (6) of the objectives identified in the Institute of Medicine (IOM) Report, including Assessment, Policy Development and Assurance including:

- ASSESSMENT:** MONITOR HEALTH: This project is primarily built on the need for conducting surveillance using hospital data linked with environmental data. Diagnose and Investigate: success of this project will be to use data to help better understand the relationship between health and environmental health.
- ASSURANCE:** Ensure Effectiveness: Having a DSA will enable the Florida EPHTN to evaluate and measure progress of intervention and prevention efforts.
- POLICY DEVELOPMENT:** Inform, Educate and Empower: By using the data from this project, will be used to inform stakeholders, communities about how their health may be impacted by environmental hazards.
- Mobilizing Community Participation:** The end results after formulating a DSA and providing researchers with data needed to produce results in a more timely fashion may help to mobilize and engage community participants, particularly stakeholders to identify environmental hazards and the need of environmental interventions.
- Develop Policies:** With a successful project, a data sharing agreement may open a national policy effort for all state health care administration agencies to share data with their Department of Health.

Conclusions

In summary, the system thinking approach using the shifting the burden and fixes that backfire archetypes, helped to propel this project towards identifying obstacles to reach resolution. The result of the work effort of this leadership project helped to stimulate a heightened interest between agencies of sharing hospital data. Although a formal data share data on a recurring basis between agencies has not materialized, an interagency data request application was developed. More importantly, a communication channel has been established, and management is keenly aware of the need for a more collaborative effort to partner to share data. At the National level, this project is supported by the CDC Environmental Public Health Tracking Branch, National Association Health Data Organization and several other Health Tracking funded states. The National Association of Health Data Organization (NAHDO) has been working to make DSA's between health care agencies and health departments a reality among states. Currently, NAHDO and CDC are assisting a national work group effort to develop a uniform DSA that can be used by at a national level. Florida Department of Health is involved with this federally funded Environmental Public Health Tracking states to work on this issue at a national level.

Next steps include continuing to participate at the state and national levels in workgroups and to advocate the need for agencies to develop DSA's and to share hospital data.

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For further information

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