Responses to legal questions about data sharing

QUESTIONS POSED

In anticipation of questions and requests regarding the legal-issues with data sharing, please reply to the following:

1. Is your inter-jurisdictional sharing permitted or barred under a formal agreement (e.g., a law (e.g., HIPAA) or public health authority) or informal agreement ("handshake", MOU, information sharing, etc.)?
2. If 'yes' to #1, please provide copy or hyper-link to the relevant legal agreements (templates), laws, rules, or other (either permissive or preventing)
3. For your agency, on whose authority can inter-jurisdictional data sharing be granted for…
    a. Health agency to health agency
    b. Health agency to other governmental agency; e.g., public safety

RESPONSES

Florida Department of Health (David Atrubin)

1. Inter-jurisdictional sharing of de-identified data (e.g., from state to state) is neither expressly permitted or barred in Florida. For us to routinely share data with other states or municipalities, additional discussion would need to occur within the FDOH. Here is our MOU (or a part of it) below. The collection of SyS data in FL falls under epidemiologic investigation.

RECITALS

I. Department has the duty to assess the public health status and needs of the state through statewide data collection. §381.0011(1), F.S.

II. Department's Bureau of Epidemiology is instituting a statewide epidemiological investigation of syndromes amongst emergency room patients to identify and monitor disease outbreaks in the community.

III. This epidemiological investigation will enable earlier identification of natural and manmade outbreaks of diseases of public health significance thereby triggering much earlier detection for the Department's diagnosis based surveillance system. §381.0031, F.S.

IV. HIPAA does not govern Department epidemiological investigation. 45 CFR §160.203(c).

V. HIPAA does not require a Hospital to have an authorization or offer an opportunity to agree or object before disclosing protected health information as part of Department's epidemiological investigations. 45 CFR §164.512(b)(1)(i).

VI. Hospital is a facility licensed under chapter 395, Florida Statutes.

VII. Department has the authority to examine patient records in any licensed facility for purposes of epidemiological investigation. §395.3025(5), F.S.

VIII. Information gathered from such patient records is confidential and exempt from disclosure under Florida's public records laws and may not be further disclosed to non-Department personnel in a manner that reveals the patient's identity. §395.3025(7)(a), F.S.

IX. Department acknowledges that an epidemiological investigation of this scope cannot be done in an unobtrusive manner with Department personnel at Hospital.

Here is the section of Florida's reportable disease code that, I believe, most closely applies to the sharing of SyS data. What is clear to me is that the language was written for data that are not SyS in nature. An update would be beneficial.

64D-3.036 Notifiable Disease Case Report Content is Confidential.

All information contained in laboratory reports, notifiable disease or condition case reports and in related epidemiological investigatory notes is confidential as provided in Section 381.0031(6), F.S., and will only be released as determined as necessary by the State Health Officer or designee for the protection of the public's health due to the highly infectious nature of the disease, the potential for further outbreaks, and/or the inability to identify or locate specific persons in contact with the cases.

Rulemaking Authority 381.0011, 381.003(2), 381.0031(8), 384.33, 392.66 FS. Law Implemented 381.0011(3), 381.003(1), 381.0031(2), (6), (7), 384.25, 392.53 FS. History–New 11-20-06.

Houston Health Department, Texas (Tolu Olumuyiwa)

1. For our region, sharing is permitted through a charter with the members of the Syndromic Surveillance Consortium of Southeast Texas (see next page).

Syndromic Surveillance Consortium of Southeast Texas (SSCSeT)
Charter and Bylaws
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ARTICLE I: NAME

Section 1.1 Name. The name of the organization shall be “Syndromic Surveillance Consortium of Southeast Texas” and shall be referred to within this document as “the Consortium”.

ARTICLE II: PURPOSE AND SCOPE

Section 2.1 Purpose. The purpose of the Consortium is to bring together jurisdictional public health agencies, health data providers and other relevant stakeholders primarily in Public Health Region 6/5S to collaborate and coordinate on matters of science, policy, and utilization of technological advances in syndromic surveillance as it pertains to the syndromic surveillance system installed and operated by the Houston Health Department which shall be referred to as “the Network”.

Section 2.2 Scope. The scope of the consortium shall be limited to the following items:

1) Communication and collaboration with other syndromic surveillance initiatives be they statewide, national, or international
2) Jurisdictional etiquette regarding data collection, sharing and use
3) Provider outreach
4) Building regional expertise in the areas of Meaningful Use and HL7 messaging standards
5) Research and public health practice
6) Training and utilization of system features
7) Education regarding acceptable uses of the technology which will include best practices
8) Communication regarding system issues affecting usability, service level agreements and costs
9) Assuring transparency of technology and operations to all members

ARTICLE III: MEMBERSHIP

Section 3.1 Definitions

3.1.1 “Members” are the participating Jurisdictions, Providers, and Stakeholders that form the Consortium

3.1.1.2 “Jurisdictions” are public health departments that provide epidemiological and disease control services for a given geographical region that choose to participate in the Consortium.

3.1.1.3 “Providers” are health care institutions providing patient treatment that submit syndromic data to the Network and may be further classified by size or type.

3.1.1.4 “Stakeholders” are groups, organizations or institutions with an interest in syndromic surveillance in southeast Texas who may affect or be affected by policies and activities of the Consortium.

3.1.2 "Representatives" are individuals who attend Consortium meetings and conduct Consortium business at the behest of their Member agency. Members are not limited in the number of Representatives who may attend meetings or conduct business.

3.1.3 "Participation"

3.1.3.1 Participating Jurisdictions are those cooperating jurisdictions having one or more providers submit syndromic data to the Network.

3.1.3.2 Participating Providers are health care institutions that submit data to the Network.

3.1.3.3 Participating Stakeholders are those invited groups, organizations or institutions that attend Consortium meetings regularly.

3.1.4 "Seats" for voting are the allotted to Members of the Consortium and shall be filled by any Member's Representative. Seated Representatives shall vote on Consortium business including motions and the election of officers.

Section 3.2 Apportionment of Seats

3.2.1 One (1) Seat shall be allotted to each Jurisdictional Member. The founding Jurisdictional Members in the Consortium are the Texas counties of Brazoria, Chambers, Fort Bend, Galveston, Hardin, Harris, Jefferson, Montgomery, and Orange and the City of Beaumont, the City of Houston and the City of Port Arthur. Additionally a seat is allotted to DSHS Region 6/5S covering the Texas counties of Austin, Colorado, Liberty, Matagorda, Walker, Waller, and Wharton.

3.2.2 One (1) Seat shall be allotted to each type of participating Provider:

3.2.2.1 Emergency Centers whether stand alone or attached to a hospital

3.2.2.2 Inpatient Hospitals

3.2.2.3 Outpatient Clinics including Urgent Care Centers

3.2.2.4 Eligible Professionals as defined by the Medicare EHR Incentive Program

3.2.3 One (1) Seat shall be allotted to each of the following Stakeholders:

3.2.3.1 Gulf Coast Regional Extension Center (GCREC)

3.2.3.2 SouthEast Texas Regional Advisory Council (SETRAC)

3.2.3.3 University of Texas Health Science Center at Houston School for Biomedical Informatics

3.2.3.4 Greater Houston Healthconnect Health Information Exchange (GHHIE)

Section 3.3 Addition and Removal of Seats
Seats shall be added by 2/3ds vote of the Consortium. Seats are eligible for removal in the event that a Member ceases participating in the Network and shall be dissolved by 2/3ds vote.

ARTICLE IV: OFFICERS

Section 4.1 Service: Officers shall serve as conveners, organizers and communicators, but without different or greater authority than each general member and shall be elected from the body of Jurisdictional Representatives.

Section 4.2 Nominations: Any Seated member may nominate any attending Representative.

Section 4.3 Terms: Each Officer shall serve one (1) term and each term shall last no longer than twenty four (24) consecutive months. No officer shall be eligible for reelection to the same position within six (6) years of election.

Section 4.4 Positions

4.4.1 Chair convenes and leads meetings, prepares meeting agenda items with assistance from the Secretary and calls special meetings

4.4.2 Vice Chair assists the Chair, and leads meetings in the absence of the Chair

4.4.3 Secretary maintains FTP/website/email/communications, coordinates the meeting agenda with the Chair, takes minutes during meetings and distributes agendas and minutes to Member Representatives

Section 4.5 Elections. Election of officers may be held by anonymous Doodle or other similar type poll. (This sentence needs clarification) redacted

ARTICLE V: MEETINGS

Section 5.1 Regular Meetings. Regular meeting will be held quarterly.

Section 5.2 Special Meetings. Special meetings can be called as needed by any Consortium member after approval from the Chair and coordinated through the Secretary

ARTICLE VI: COMMITTEES

Section 6.1 Committees. Committees shall be formed for achieving the goals of the group and guided by the purpose and scope outlined in ARTICLE II.

6.1.1 Committees may be standing or temporary and serve at the pleasure of the Consortium.

6.1.2 Committees develop policies for approval as well as implement approved polices and generally carry out the work of the Consortium.

6.1.3 Persons serving on Committees are assigned by Consortium Members. These persons may not necessarily represent their Member agencies at Consortium meetings but are assigned according to the needs of their Member agency.

ARTICLE VII: GOVERNANCE

Meetings shall be governed by general guidelines established in the latest edition of Robert's Rules of Order.

ARTICLE VIII: POWERS

Section 8.1 In relation to Network-wide affairs:

8.1.1 The Consortium shall have the authority to set policy for the fair use of the Network by Consortium Members and for the resolution of issues as set forth in ARTICLE I of this charter.

Section 8.2 In relation to statewide affairs:

8.2.1 The Consortium shall have the authority to represent the Network to the DSHS Syndromic Surveillance Governance Council via communication through the PHR 6/5S Regional Advisory Committee.

Section 8.3 In relation to affairs outside the state:

8.3.1 The Consortium shall have the authority to represent the Network on issues of syndromic surveillance to appropriate entities outside the State of Texas.

ARTICLE IX: AMENDMENTS TO THE BYLAWS

Section 9.1 Amendments. These bylaws can be amended at any regular or special meeting providing that previous notice was given at the prior meeting in writing and sent to all members of the consortium by the secretary. Previous notice can be sent by email. Amendments can be passed by 2/3s vote.

ARTICLE X: Quorum

Section 10.1 Quorum. A Quorum is established when fifty one per cent of seats are filled at Consortium meetings.

North Carolina Division of Public Health (Zach Faigen)

1. NC is allowed to share data with CDC according to our mandate that allows for the collection of the ED data. I believe legally this is referring to the raw line level data, not sharing aggregate data or reports etc. Our mandate is attached.

§ 130A-480. Emergency department data reporting.

(a) For the purpose of ensuring the protection of the public health, the State Health Director shall develop a syndromic surveillance program for hospital emergency departments in order to detect and investigate public health threats that may result from (i) a terrorist incident using nuclear, biological, or chemical agents or (ii) an epidemic or infectious, communicable, or other disease. The State Health Director shall specify the data to be reported by hospitals pursuant to this program, subject to the following:

(1) Each hospital shall submit electronically available emergency department data as specified by rule by the Commission. The Commission, in consultation with hospitals, shall establish by rule a schedule for the implementation of full electronic reporting capability of all data elements by all hospitals. The schedule shall take into consideration the number of data elements already reported by the hospital, the hospital's capacity to electronically maintain the remaining elements, available funding, and other relevant factors.

(2) None of the following data for patients or their relatives, employers, or household members may be collected by the State Health Director: names; postal or street address information, other than town or city, county, state, and the first five digits of the zip code; geocode information; telephone numbers; fax numbers; electronic mail addresses; social security numbers; health plan beneficiary numbers; account numbers; certificate or license numbers; vehicle identifiers and serial numbers, including license plate numbers; device identifiers and serial numbers; web universal resource locators (URLs); Internet protocol (IP) address numbers; biometric identifiers, including finger and voice prints; and full face photographic images and any comparable images.

(b) The following are not public records under Chapter 132 of the General Statutes and are privileged and confidential:

(1) Data reported to the State Health Director pursuant to this section.

(2) Data collected or maintained by any entity with whom the State Health Director contracts for the reporting, collection, or analysis of data pursuant to this section.

The State Health Director shall maintain the confidentiality of the data reported pursuant to this section and shall ensure that adequate measures are taken to provide system security for all data and information. The State Health Director may share data with local health departments and the Centers for Disease Control and Prevention (CDC) for public health purposes. Local health departments are bound by the confidentiality provisions of this section. The Department shall enter into an agreement with the CDC to ensure that the CDC complies with the confidentiality provisions of this section. The State Health Director shall not allow information that it receives pursuant to this section to be used for commercial purposes and shall not release data except as authorized by other provisions of law.

(c) A person is immune from liability for actions arising from the required submission of data under this Article.

(d) For purposes of this section, "hospital" means a hospital, as defined in G.S. 131E-214.1(3), that operates an emergency room on a 24-hour basis. The term does not include a psychiatric hospital that operates an emergency room.

(e) Administrative emergency department data shall be reported by hospitals under Article 11A of Chapter 131E of the General Statutes. (2004-124, s. 10.34(b); 2006-264, s. 64(a); 2007-8, s. 1.)

Tennessee Department of Health (Caleb Wiedeman)

1. Well... maybe? All potentially relevant documentation is below.

TCA 1200-14-01-.15 "General Measures for the Effective control of Reportable Diseases".

1200-14-01-.15 GENERAL MEASURES FOR THE EFFECTIVE CONTROL OF REPORTABLE DISEASES.

(1) The local health officer or the Commissioner or a designated representative of the Commissioner, upon receiving a report of a reportable disease or of a suspected epidemic of disease or of a suspected case of a disease of public health significance or event, shall:

(a) Confer with the physician, laboratory, hospital, or person making the report;

(Rule 1200-14-01-.15, continued)

(b) Collect such specimens for laboratory examination as may be necessary to confirm the diagnosis of the disease and/or to find the source of the infection or the epidemic;

(c) Obtain all names and information necessary to identify and contact all persons potentially exposed to the source of the disease outbreak as needed to protect the public health;

(d) Make a complete epidemiological investigation to include (but not limited to): review of appropriate medical and laboratory records of affected persons and controls, interviews of affected persons and controls, and recording of the findings on a communicable disease field record; and

(e) Establish appropriate control measures which may include examination, treatment, isolation, quarantine, exclusion, disinfection, immunization, disease surveillance, closure of establishment, education, and other measures considered appropriate by medical experts for the protection of the public's health.

Authority: *T.C.A. §§ 4-5-202, 68-1-103, 68-1-104, 68-1-201, 68-5-101, and 68-5-104.* ***Administrative History:*** *Original rule certified June 7, 1974. Repeal and new rule filed March 31, 1977; effective May 2, 1977. Amendment filed April 20, 1987; effective June 4, 1987. Amendment filed March 30, 2004; effective July 29, 2004. Emergency rule filed October 8, 2009; effective through April 6, 2010. Amendment filed December 29, 2009; effective March 29, 2010.*

The TCA for confidentiality is below:

1200-14-01-.17 CONFIDENTIALITY.

All individually identifiable health information collected, created, and/or prepared by the Department is deemed confidential and shall not be considered a public record. The Department may disclose such information to those entities or persons as are necessary to carry out the purposes of these Rules and 1200-14-04-.01 et seq. or as otherwise authorized or required by law.

Authority: *T.C.A. §§ 4-5-202, 68-1-103, 68-1-104, 68-1-201, and 68-5-104.* ***Administrative History:*** *Original rule certified June 7, 1974. Repeal and new rule filed March 31, 1977; effective May 2, 1977. Repeal filed January 11, 1994; effective March 27, 1994. New rule filed March 30, 2004; effective July 29, 2004.*

And our trading partner agreements highlight that the data we receive will be used for "public health business practice".

TDH's general public data release policy is below (although it is currently being revised):

HEALTH DATA RELEASE POLICY
RELEASE OF AGGREGATED DATA

The Tennessee Department of Health has the responsibility to protect the confidentiality and privacy of the citizens while also adequately presenting information and data concerning conditions that affect public health. With regard to these two responsibilities, the following guidelines should be followed when presenting data for public consumption including publications or public web sites:

Rates

(1) Any rate may be presented if the population at risk is at least 100 persons. If the population is less than 100, the rate may be presented in certain circumstances as noted in the Exceptions section below. If all Exception criteria are not met, the rate will be suppressed (replaced with an asterisk or similar symbol) and a footnote added to the page indicating "rate not calculated due to population less than 100".

Numbers

1. Counts for the state, region and county totals can be shown irrespective of the number of events or population size.
2. Counts for state, region and county totals, by sex, can be shown irrespective of the number of events or population size.
3. Counts for state, region and county totals, by race, can be presented if the number of persons in each race group being presented is a least 50.
4. Counts for state, region and county totals, by race and sex, can be presented if the number of persons in each race-sex category presented is at least 50.
5. Counts for the state, region and county totals, by age group can be presented if the number of persons in each age group presented is at least 50.

Exceptions

1. If the Rates criteria are not satisfied, rates may be presented only if both of the following conditions are met:
   a) Appropriate confidence intervals are presented with all rates.
   b) Table cell subtracted from the number of total events in the same data file for the same characteristic is at least 10 ("Numerator and Denominator Rule").
2. If the Numbers criteria are not satisfied, counts may be presented only if the following condition is met:
   a) Table cell subtracted from the number of total events in the same data file for the same characteristic is at least 10 ("Numerator and Denominator Rule").

It is understood that a program within the Department of Health may adopt more strict (conservative) guidelines for data presentation. In addition, specific situations related to a public health threat could dictate more detailed data presentation, at the direction of the Commissioner of the Department of Health.

Some of our (informal) trading partner agreements have specific amendments that our partner organizations required and the contents of these varies.

3.a. Health agency to health agency for public health use cases would be okay if the public health authority is legally authorized to collect or receive the information for the purpose of preventing or controlling disease, injury, or disability.

3.b. Health agency to other government agency would probably require legal review or IRB approval if it involved PHI (any line level information). Otherwise, it would be subject to our public data release guidance.