

**Assessing the legal challenges of data sharing
across HIV, TB, STD and viral hepatitis within
the NYC Department of Health and Mental
Hygiene (DOHMH)**

**Program Collaboration and Service Integration (PCSI)
New York City Department of Health and Mental Hygiene
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Background

A. Program Collaboration and Service Integration (PCSI)

Program Collaboration and Service Integration (PCSI) is a CDC funded initiative, within the New York City (NYC) Department of Health and Mental Hygiene (DOHMH) Division of Disease Control, designed to strengthen collaborative work across HIV/AIDS, STD, TB and viral hepatitis programs and facilitate integration of services provided to the public. The mission of PCSI is to work with DOHMH programs and with clinical and non-clinical providers to improve the health of people with and at risk for multiple diseases by increasing knowledge about these diseases and maximizing opportunities for testing, vaccination, and treatment. During the first year of the PCSI initiative, October 2010 through September 2011, PCSI staff examined the epidemiology of HIV, STDs, TB, and viral hepatitis in NYC, as well as opportunities for program collaboration and service integration across the DOHMH programs that work on these disease areas. Findings from interviews with DOHMH staff described past and current data sharing projects as well as a need for clarification about laws and policies to maximize opportunities for data sharing. We found that staff were not always well informed about the laws for diseases outside their Bureau and this lack of clarity hinders data sharing. Overall, staff described a common interest in sharing surveillance data to inform public health activities and improve clinical services. In order to foster increased data sharing, PCSI staff worked with the General Counsel's office to examine existing New York State (NYS) and City (NYC) laws governing reporting and permissible disclosure of disease-related information.

Laws governing disease surveillance are generally left to the state and local legislatures and public health agencies.¹ Laws and regulations for reporting and disclosing case information came into existence at different times, driven by a specific need, such as the recognition of a new

public health problem. Data confidentiality was addressed differently depending on the disease or prevailing standards at the time. The result has been an array of diverse policies regarding access to confidential information and its subsequent use, which does not necessarily reflect how a health department needs to operate to fulfill its broader mission of protecting public health. In NYC, these laws create a situation in which sharing surveillance data between programs, even within a single health department, may constitute an impermissible disclosure of confidential disease information.

B. Objectives

This paper describes how federal, state, and city laws impact data sharing within the DOHMH across HIV/AIDS, STD, TB, and viral hepatitis programs, focusing primarily on surveillance data.² First, we define two different types of data sharing, delineating the reasons data are shared and the way in which data are shared within the DOHMH. Second, we analyze NYS and NYC laws governing reporting and permissible disclosure of disease-related information. Third, we describe how laws and regulations have impacted the surveillance and data sharing policies implemented by the DOHMH. Finally, we recommend changes to the law and data sharing practices that will allow the DOHMH to improve infectious disease control in NYC.³ Overall, this document is intended to make clear the current laws regarding data sharing and provide a catalyst for program staff to discuss opportunities to share data when permissible and warranted by a public health need.

C. Overview of NYC DOHMH and the Division of Disease Control

New York City is the largest city in the United States with a population of approximately 8.2 million people⁴ and has the highest population density at more than 27,000 people per square

mile.⁵ With an annual budget of \$1.6 billion and more than 6,000 employees throughout the five boroughs, the NYC DOHMH is one of the largest public health agencies in the world.

While there are several Bureaus at DOHMH that work on issues relevant to populations at risk for the PCSI diseases, the Division of Disease Control is the DOHMH Division responsible for the identification, surveillance, treatment, control and prevention of infectious diseases including HIV/AIDS, STD, TB and viral hepatitis. The Division of Disease Control is separated into 6 Bureaus; Bureau of HIV Prevention and Control, Bureau of Sexually Transmitted Disease Prevention, Bureau of Tuberculosis Control, Bureau of Immunization, Bureau of Communicable Disease and Public Health Labs. Activities related to viral hepatitis are located in three separate areas.

The mission of the Bureau of HIV Prevention and Control (BHIV) is to prevent new HIV infections and reduce morbidity and mortality among HIV-infected persons. BHIV conducts surveillance and partner notification activities. It is also tasked with helping the community plan programs and allocate government funds for HIV/AIDS programs and services in NYC throughout the 5 boroughs, and promoting HIV testing programs and linkage to care for people living with HIV/AIDS. As of April 2012, the HIV registry contains 221,000 unique individuals, living and dead. BHIV only provides client level services in the context of partner notifications, and does not provide HIV treatment.

The Bureau of Sexually Transmitted Disease Control (BSTD) aims to promote sexual health and reduce the impact of sexually transmitted infections among New Yorkers through the provision of direct clinical services and partner services. BSTD provides free sexual health services in 9 STD/HIV clinics located New York City. Services at these clinics include screenings and treatment for STDs, HIV counseling and testing, and partner services. BSTD

also partners with community groups, private providers and other agencies; conducts research; and develops policies to improve sexual health and wellness. BSTD conducts surveillance on several sexually transmitted diseases including chlamydia, gonorrhea and syphilis. In 2010 there were 63,544, 12,354 and 955 cases of chlamydia, gonorrhea and syphilis, respectively reported to BSTD.

The mission of the Bureau of Tuberculosis Control (BTBC) is to prevent the spread of tuberculosis and offers direct patient care at 4 clinics throughout NYC. Activities include TB prevention education, disease surveillance, outbreak investigations and outreach. BTBC educates physicians, community groups, and the general public about effective treatment and prevention of TB. 708 cases of TB were reported in 2010.

Viral hepatitis is covered by three programs within DOHMH: Office of Viral Hepatitis Coordination (OVHC), Bureau of Immunization (BOI) and Bureau of Communicable Disease (BCD). OVHC works cooperatively with service providers, within DOHMH and throughout the community, to provide current information on viral hepatitis to the public, and to develop and enhance programmatic interventions for promoting viral hepatitis prevention and care. BOI is responsible for increasing vaccine coverage to prevent the occurrence and transmission of vaccine preventable diseases among New Yorkers, including hepatitis A and B. BOI provides services in four immunization clinics located in Brooklyn, Manhattan, Queens and the Bronx. BOI also houses the perinatal hepatitis B program responsible for surveillance and case management of pregnant women with hepatitis B and their infants. BCD is responsible for surveillance of hepatitis A, B and C, as well as many other infectious diseases. BCD staff investigates disease outbreaks, collects and analyzes data on disease trends, educates the public and medical community regarding disease prevention and treatment, monitors emerging

infectious diseases, and provides active surveillance for waterborne diseases. There were 11,640 cases of hepatitis B and 10,759 cases of hepatitis C reported in 2010 to BCD.

The Office of General Counsel provides legal advice to the agency, including guidance about how to comply with applicable confidentiality laws, rules and regulations. The Chief Privacy Officer is tasked with reviewing program protocols, advising on policies and drafting data use agreements as needed. She also performs breach investigations and notifications.

Data Sharing

For the purposes of this paper, we separate data sharing into two broad categories: 1) linkage projects which involve merging data from disease surveillance registries to conduct retrospective aggregate epidemiologic analyses, and 2) sharing identifying information about individual cases, or person-level surveillance data, across programs. Both types of data sharing rely on the use of identifying information which may include a person's name, address, date of birth, date of death, Social Security Number (SSN), or date of admission to a hospital. For the first category, identifying information of an individual case is used initially to link records from two or more surveillance registries.⁶ After the records have been linked, the identifying information is removed and a dataset with analytic variables remains for aggregate analysis. Such analyses can inform program-planners and policy-makers on many aspects of disease, including risk factors for outcomes examined.

It is important to note that while identifying information such as name, date of birth, and address are not included in an analytic dataset resulting from data linkages, line listed data used for aggregate analyses may still contain potentially identifiable information. Because there may be potential for re-identification, some analytic datasets may be considered highly sensitive and highlight the need for data sharing agreements. Alternatively, potentially identifying variables can be masked. For example, all dates can include only month and year. Once a match has been

completed, where and how these analytic datasets can be used within DOHMH are not legal questions, but policy and security issues. These issues can be addressed through internal data sharing agreements, written and signed prior to the match, which stipulate how linked datasets are to be stored and who has access to them. These issues can also be addressed by program policies.

The second category of data sharing focuses on access to person-level data across Bureaus. This type of data sharing can have a variety of purposes beyond epidemiology and therefore the use must be assessed to see if it is permitted by law. Sharing information about an individual person can be for distinct reasons, therefore, each separate law must be analyzed. The use must be permitted by law. For example, a disease-specific program may wish to use another program's data to find an individual's more accurate or current locating information in order to provide notice of potential disease exposure. In another case, a program may want to obtain an individual's demographic information from another program to improve the quality of surveillance data; for example, by having more complete race/ethnicity data, a program may be able to better measure the impact of a disease on a particular demographic group and better target resources to that group. Finally, programs may need to share individual level disease information to direct services. One example is BSTD staff needing to know the HIV status of the partners of an HIV-infected syphilis case, so that they can prioritize notification of those partners not known to be HIV-infected.

Legal Use and Access to Data

While disease reports are made or forwarded to the DOHMH as an agency, the disease registries are managed by individual programs, and access to those reports may be limited by disease-specific laws and security/confidentiality policies. The first type of data sharing, described above as linkage projects which involve merging data from disease surveillance

registries to conduct retrospective de-identified aggregate epidemiologic analyses, are generally permissible under the existing laws for several reasons. First, all the laws permit epidemiologic use; second, privacy interests are carefully protected during the linkage stage; third, no identifying information is retained for analysis; and fourth only aggregate data are released. Currently, the laws governing the use of STD data inhibit DOHMH's ability to share some surveillance data internally.

Even in the absence of restrictions on use, internal policies are necessary to protect the confidentiality of identifiable information. Basic tenets of confidentiality policy are that only people whose job it is to work with confidential data should have access to that data—in other words, data should be shared with only those with a need to know. Moreover, the data to be shared should contain only the minimum necessary information. For example, a Social Security number may be collected by a program for billing purposes, but if another program is allowed access to demographic data to complete their surveillance records, there is no need to share that Social Security number. Similarly, the billing person does not need a patient's risk factors for a sexually transmitted disease.

Laws governing surveillance data are a matter of state and local purview. The primary federal law governing patient confidentiality for medical information is the Health Insurance Portability and Accountability Act (HIPAA), but it does not govern the surveillance data at issue in this paper. HIPAA allows medical providers to report patient disease information to public health agencies without patient consent, but it plays no role in the intra-agency data sharing issues covered by this paper.⁷

Developments in New York State and City Surveillance Laws

Disclosure of protected individual-level case information from a disease surveillance registry in New York City is regulated both by the New York State Public Health Law and the

State Sanitary Code at the State level, and the New York City Health Code at the City level (Appendix A). As seen in Table 1, New York’s mandatory case reporting and confidentiality laws were passed at different times for each disease group, and the laws themselves vary in reporting requirements and permissible disclosures. In addition to requirements that physicians and medical institutions report diseases, the laboratories conducting the tests are also obligated by law to report cases of communicable diseases.⁸ The State Sanitary Code also creates a duty of any head of household or person in charge of any institution, school, or other groups of people to report cases of diseases that may be communicable.⁹

Table 1. New York State and City confidentiality laws for the PCSI disease areas, and date of initial surveillance efforts in the state.

Disease	First NY Surveillance	State Law	Date of Passage	Amended	NYC Law	Date of Passage	Amended
TB	1897 ¹⁰	Pub. Health Law § 2221	1953	1956	Health Code § 11.21	1991	1993, 2008, 2010
Viral Hepatitis	1952 ¹¹	Pub. Health Law § 18 (General provision)	1986	1987, 1990, 1991, 1992, 1998, 1999, 2004, 2010	Health Code § 11.11	1991	1993, 2008
STDs	1912 ¹²	Pub. Health Law § 2306	1980	1992, 2010	Health Code § 11.11	1991	1993, 2008
HIV/AIDS ¹³	1989 ¹⁴	Pub. Health Law § 2135	1998	2010	N/A		

D. Reporting Diseases for Case Surveillance

Mandatory reporting of specific diseases and conditions was enacted as a response to a public health need for prevention and management of those diseases. As a result, the laws and regulations governing reporting can be found in different sections of the Public Health Law and NYC Health Code. However, the actual reporting requirements are very similar, with the exception of HIV reports.

New York City was one of the earliest jurisdictions to implement a reporting system for sexually transmitted diseases (STD). Although the term ‘venereal’ was used in the original laws, it has been replaced with ‘sexually transmitted.’ The City implemented a two-tiered system of reporting for institutions and private physicians in 1912. Institutions were required to disclose the patient’s identity; private physicians were not.¹⁵ In 1963, the NYC Health Code began mandating physicians and institutions report to DOHMH all cases of syphilis and gonorrhea with the patient’s identity disclosed to DOHMH in all circumstances.¹⁶ Chlamydia was not added to the NYC Health Code until 1992. STD provider reporting is required in the rest of the state to the New York State Department of Health (NYSDOH).¹⁷ TB is also reportable to DOHMH in New York City, and to the NYSDOH for the rest of the State.¹⁸ The current State law for TB reporting was enacted in 1953,¹⁹ and the TB-specific provision to the NYC Health Code was enacted in 1991.²⁰ The NYC Health Code provisions for TB envision a system in which the DOHMH tracks the case from diagnosis to cure or death. In NYC, physicians must report not only suspected and confirmed TB disease, but also the treatment plan and the cessation of treatment to the NYC DOHMH. The DOHMH must also approve any proposals for infectious patients to be discharged from the hospital,²¹ and both the City and State must be notified when a patient with tuberculosis dies or is cured.²²

Viral hepatitis surveillance is the least regulated of the four PCSI disease areas. While hepatitis reporting began in New York as early as 1952, there is no current state law or regulation that deals specifically with hepatitis surveillance; rather, it is included in the general provisions for physicians and institutions to report cases of communicable diseases.²³ Likewise, reporting of viral hepatitis at the City level is governed by a general Health Code provision for reporting communicable disease. Hepatitis A, B, C, D (“Delta Hepatitis”), and “other suspected infectious

viral hepatitis” are now on the list, which means that “[c]ases and carriers affected with [...] the disease [...] shall be reported to the Department.”²⁴

Laws and regulations for reporting and disclosure of HIV-related information are distinct from those for other STDs. A regulation was enacted in 1989 as an emergency measure to require reporting of all cases of AIDS to the State DOH Commissioner.²⁵ The State legislature did not enact a reporting statute until 1998, which required physicians or laboratories aware of a positive HIV test to report HIV lab results to the State.²⁶ Unlike lab reports for the other PCSI diseases in NYC, all case reports of HIV/AIDS go directly to NYSDOH; cases are not directly reportable to the City. A physician who diagnoses a person with HIV infection reports directly to the DOHMH pursuant to an agreement with NYSDOH, but the laboratory that conducts the test and gets a positive result, must immediately report the result to the State Commissioner, who in turn informs the local health commissioner or public health officer of the municipality where the infection occurred.²⁷ Nearly 80% of all HIV cases in New York State originate in NYC.²⁸ An agreement between the State and the City governs how this information is transmitted and historically, has tracked the State law regarding the limits on how the HIV surveillance data can be used.²⁹

E. Permissible Usage of Reported Surveillance Data

As with the variance in reporting rules, there are some differences between the disease groups for how the data can be used, particularly for HIV/AIDS and STDs.

HIV/AIDS

As noted above, the New York State legislature first enacted a separate chapter of the Public Health Law that dealt with HIV disclosure, partner notification, and confidentiality in 1998.³⁰ Until 2010, information from HIV case reports in New York State could only be used

for epidemiologic monitoring and partner notification.³¹ In practice, this meant that each request for access to the HIV registry, even if from within DOHMH, had to be assessed on an individual (case by case) basis to evaluate whether the proposal constituted a permissible use. These requests were initially fielded by the HIV surveillance unit, with consultation from the Office of the General Counsel when needed. Linkage projects with other disease surveillance registries were allowed since they fit within the permissible “epidemiologic monitoring” use. When the agency expanded its partner notification efforts in both the HIV Field Services Unit, as well as in the STD program, HARS access was allowed for partner notification. For example, named partners could be looked up to see if they were HIV positive in order to prioritize notifications.

An amendment to the law in 2010 expanded this statute and permitted additional uses of registry information by public health disease programs, including assessment of co-morbidity or completeness of reporting.³² Disclosures of HIV case information are also permitted if they serve “to direct program needs,” or, if data are used in the aggregate, to inspect the quality of care by agencies contracted by the state or local government to provide health care or other services.³³ In NYC, the HIV surveillance registry not only includes the HIV diagnosis, but additional clinically relevant information such as the CD4 count and viral load.³⁴ However, even with the new uses regarding co-morbidity, completeness of reporting, and program needs, the law stipulates that “patient specific identifying information shall not be disclosed outside the state or local health department.”³⁵ This means the health department can now share individual-level HIV data with another program within the department that provides direct services. While STD or TB clinics operated by DOHMH can obtain HIV registry data, external clinics and treatment providers are still not allowed to find out a patient’s HIV status from the registry³⁶.

The 2010 amendment is a major step towards improving public health by allowing critical HIV-related information to be used for broader purposes within the health department.

STDs

The relevant State law for STDs states that, “[a]ll reports or information secured by a board of health or health officer under the provisions of [the STD article] shall be confidential except insofar as is necessary to carry out the purposes of this article.”³⁷ The “purposes of this article” are defined as STD control and treatment. This language means that disclosures, even within the DOHMH, are only allowed for reasons directly related to STD control and treatment. There are some other limited exceptions that allow for disclosure in certain judicial proceedings.³⁸ Courts have interpreted this provision strictly, stating it “is integral to a statutory scheme designed to encourage afflicted persons to seek and secure treatment, which in the case of communicable disease serves individual interests as well as those of society.”³⁹

Under the NYC Health Code, individually identifiable STD-related surveillance data collected by DOHMH are confidential and should not be disclosed. Moreover, disclosure cannot be compelled.⁴⁰ There is a general exception for disclosing information to outside entities, including to “a physician or institution providing examination or treatment [...], to an agency approved by the Department for prevention, treatment or social service, or to any person when necessary for the protection of public health”⁴¹ (Appendix B). This allows outside entities to receive information for public health purposes, as long as only the minimal information necessary for the exception purpose is disclosed.⁴²

Reading the Health Code and the State law together, disclosures to an internal DOHMH program or outside entity can be made if the purpose for disclosure is directly related to the care and treatment of the STD, not for a general public health purpose.⁴³ This is an example of how

legal restrictions on the use of the surveillance data impact who within the DOHMH has access to it. The STD program can answer a community physician's questions about prior STD treatment using the surveillance registry, but cannot provide an address from that same registry to the DOHMH TB program to follow-up on a TB case, if there is no impact on the patient's STD care or treatment. Similarly, another surveillance group within the DOHMH cannot use the STD registry to complete its demographic information on a case.

While programs have, therefore, come to view STD surveillance data as completely inaccessible, additional internal access to the STD registry can be justified if it relates to STD care or treatment. In 2009, a protocol was approved to allow the HIV program to follow up on co-infected GC/HIV cases; the release of the individual STD names was justified because the follow up was relevant to their STD care. This could also be the case for some communicable diseases, which may be a marker for STDs. In those cases, sharing of individual patient data would be permissible. While many examples of data sharing are clearly for a valid public health purpose, the narrowly written STD law precludes widespread access. Discussions are currently underway to amend the current law to match the wording in the revised HIV law so that data can be used to assess comorbidity and to direct program needs.

Tuberculosis

Disclosure of data from DOHMH TB surveillance is governed by the same City Health Code provision as STDs, such that generally, disclosures outside DOHMH or NYSDOH are not permitted.⁴⁴ State law permits the department to disclose identifiable information if it is authorized in the sanitary code.⁴⁵ Under a provision specific to TB, the State Sanitary Code allows a health officer to use his or her own judgment to determine if disclosure of private information is in the best interest of the patient or the patient's family, and if disclosure will

contribute to the protection of public health.⁴⁶ The officer may then disclose information to official or non-official agencies “concerned with the control of tuberculosis.”⁴⁷ This is less restrictive than the STD law, as “public health” and not the direct care and treatment of a single disease, can be used to justify the disclosure. The broader uses permitting disclosure of TB status to other surveillance groups within DOHMH is allowed, so long as the disclosing party has judged that the disclosure is in the interest of public health.

Viral Hepatitis

Since there are no specific laws for reporting viral hepatitis, confidentiality is governed by general State and City provisions. The relevant city law is the general confidentiality law that applies to most reportable diseases and conditions.⁴⁸ These general provisions permit broad public health use within DOHMH as well as by NYSDOH but limit inspection by others.⁴⁹ “Appropriate information” can also be shared broadly “when necessary for the protection of public health,” as long as it is the “minimum necessary.” For example, these types of disclosures may be necessary in an outbreak of viral hepatitis. Every effort is made to protect the identity of the index case, though that case person’s identity could become known to those involved (i.e. exposed) in the outbreak. For example, if DOHMH needs to know who worked in a particular restaurant during a particular date and shift and one employee on that shift has been sick, that person’s identity might be obvious to the employer. In those situations, DOHMH will not confirm the identity or whether an absent worker is the index case, nor would DOHMH ever reveal a patient’s identity publicly.

F. Implications of Laws on Electronic Data Sharing

Much like the patchwork of laws that emerged over time, the different disease programs developed different ways of storing confidential surveillance data. Over the past 3 years, there

has been a concerted effort to consolidate databases using common software. Security and storage of data are not necessarily legal issues, but the electronic disease reporting systems used by DOHMH must comply with the reporting and disclosure requirements imposed by state and local law. The access controls and auditing functions allowed by a good system create both new opportunities as well as challenges for data sharing within the DOHMH.

Electronic Reporting

Electronic Clinical Laboratory Reporting System (ECLRS) is a reporting system developed by the New York State Department of Health (NYSDOH). The system provides laboratories with a uniform interface for reporting Communicable Diseases, Tuberculosis (TB), Sexually Transmitted Diseases (STD), HIV, Lead, and Cancer. ECLRS enables participating laboratories to use recognized standards to report positive test results over secure channels to the NYSDOH and NYC DOHMH. ECLRS is available for receiving reports 24 hours per day, 7 days per week. Reports of positive test results associated with a reportable condition will be delivered to the NYC DOHMH in real time thereby enhancing the surveillance and intervention capabilities of the Health Department. Data received through ECLRS is channeled to specific program areas at the NYC DOHMH with strict limitations on access to authorized personnel. In addition, ECLRS ensures that HIV, Lead, and Cancer test results are sent directly to the NYSDOH, while Communicable Diseases, STDs, and TB are processed only at the local level by the NYC DOHMH.

Reporting Central was developed by DOHMH to allow uniform submission of disease reports from institutions and private providers electronically. The data from both systems is encrypted.⁵⁰ Clinicians are required by Article 11 of the New York City Health Code to report certain diseases, conditions and events to the DOHMH.

G. Electronic Disease Reporting Infrastructure (eDRI) and Maven

eDRI was developed by DOHMH as an automated system that can receive, classify and clean reports from ECLRS and Reporting Central and transmit them to the specific disease-control program in a standardized format. This is an improvement over the previous system, which involved each program using different technologies, security, and data cleaning and management standards. Additional functions of eDRI include eliminating duplicate records through a matching algorithm and providing a system for different surveillance programs to share patient demographic information where permissible by law. Currently, eDRI does not retain the disease-related information, but sends the disease data to the appropriate program registry.

When eDRI was first implemented, HIV data were not included due to its limited uses, its reporting path via the State DOH, and security concerns. In light of the expansion of HIV data uses in 2010, this policy has been changed, and a process is underway to include HIV data in eDRI, which should be complete by 2013.

The individual surveillance registries, with the exception of HIV, are now managed using a software application called Maven (Consilience Software). Maven was adopted by DOHMH to transition all infectious disease surveillance except HIV/AIDS to a standardized, electronic system, replacing the individual software previously used by each surveillance program. Maven is a highly customizable surveillance, case management, and electronic workflow software system that supports over 80 reportable conditions, including vaccine-preventable diseases, STDs, TB, and others. The HIV surveillance program continues to use different software (eHARS) for surveillance. Although reports for most diseases and conditions flow through eDRI

and all but one surveillance program use Maven, no program can access another program's database in its entirety.

Maven also allows for access controls based on job functions. Currently, over 1,000 persons are using Maven from the STD, TB, and Immunization programs. However, users' access is limited, even within a Bureau, as appropriate. An STD clinic worker may only have access to cases assigned to his or her clinic, not to the universe of STD patients or reported cases. This is not strictly a legal requirement, but is good practice and complies with the minimum necessary rule that is applicable to both Health Code and HIPAA covered data.⁵¹

H. Data Sharing Among NYC DOHMH Programs

Access to specific types of data in eDRI allows surveillance programs to use individual person-level information from another program's registry through a look-up function in Maven, while remaining in compliance with state and City laws. The following fields may be available for programs to look-up: First Name, Middle Name, Last Name, Date of Birth, Address Line 1, Address Line 2, City, State, Zip Code, Email, Home Phone, Work Phone, Cell Phone, Death Date, SSN, Gender, Borough, County, Medical Record #, and Medicaid #. Information regarding the source program and disease-specific data from the original report is not available. Because of the current legal restriction on the use of STD data only for the care and treatment of STDs, case information in the STD surveillance database is not accessible to other programs through this look-up function. STD surveillance data can only be viewed by STD program staff. As noted above, exceptions could be made for specific uses, such as diagnosis with specific communicable diseases that are markers for STDs. Similarly, if a patient record is updated or merged with a duplicate record by the BTBC or BCD surveillance programs, a message can be sent by the system to eDRI. When another program views the same individual person in eDRI,

the additional demographic information contributed by the merge from the other program will be available. However, if the update is made by the STD program, the other programs will not be informed of the change. In practice, the look-up function can be used for the first two purposes of individual-level data sharing outlined in the introduction – to obtain accurate or current locating information for a patient which may be available in another database or to enrich a case report with demographic information. However, only an individual’s demographic information is currently visible through the look-up function. Disease status is not available to any other program through the look-up function; the STD program cannot see, for example, that a chlamydia case was previously reported with hepatitis B.

The final data sharing need, to obtain disease status for patient care, is not met through eDRI at this time. This restriction is not stipulated by law, but rather was a DOHMH policy decision to ensure that sensitive and confidential data on named individuals are not widely available through an electronic system used by employees throughout the Division of Disease Control. When disease status is relevant to treatment decisions for another disease and allowed by law, as in the case of a STD patient’s HIV status, the STD program is able to obtain a patient’s HIV status by phone or through a manual check of HARS, however, this is a separate, time consuming task. Ideally this information could be accessed much more quickly and efficiently, with controls in place to restrict access and protect confidentiality, through the eDRI look-up function.

Proposed Changes Underway

Optimal data sharing within the NYC DOHMH Division of Disease Control as identified in the PCSI needs assessment would allow patient demographic information originating in any disease reports to be available to all Disease Control surveillance programs, and would allow disease information to be available through the eDRI and Maven systems when necessary for

patient care and treatment, or for prioritization of partner services. Achieving optimal data sharing would require several changes to take place.

Legal Changes

Legal changes would greatly improve the ability of BSTD to share data with other programs. The additional restrictions placed on STD-related information make data exchanges between the STD surveillance program and other eDRI programs a one-way street. In the opinion of the Office of General Counsel, an amendment to the state STD law to permit data sharing for purposes other than specific management and treatment of STDs is required, unless the State Department of Health approves additional uses. This would enable DOHMH to make STD surveillance data accessible to other programs through the look up function.

Policy Changes

If additional use cases of STD data can be justified as relating to the care and treatment of STD, additional access could be assessed and evaluated. This is currently under discussion with BCD, the Bureau that oversees viral hepatitis surveillance and other communicable diseases, some of which may be markers for STD risk.

Currently, HIV surveillance data does not flow through eDRI, thus, the demographic information of HIV cases is not available to other programs through the look-up function. A process is underway to make this transition, including technical and security assessments. This change would not only allow data from the HIV registry to be shared with other programs to assess comorbidity, but will also allow the HIV program to benefit from access to TB, communicable disease, and immunization data.

A change to DOHMH policy to allow the sharing of relevant disease information through eDRI is also recommended, with proper restrictions in place to ensure that confidentiality is

protected and access is restricted. User-level restrictions in Maven could safeguard disease information so that only those staff that are currently able to access the information by phone or HARS check can access it in eDRI.

Conclusion

The CDC NCHHSTP goals of PCSI emphasize increased data sharing across HIV, STD, TB and viral hepatitis for improved public health outcomes. In order to minimize barriers and encourage data sharing, it is useful for programmatic staff to understand the state and local laws governing the control and use of data. The impetus for this report grew out of interviews with DOHMH staff to assess challenges to collaboration across programs working on HIV, STDs, TB and viral hepatitis. As part of the PCSI process at the NYC DOHMH, we identified a need to document and clarify the laws on sharing HIV, STD, TB and viral hepatitis data within the health department. It provides an opportunity to encourage data sharing by making clear what is currently permissible and what needs to be addressed by legislative change or internal policy change.

This document can serve multiple purposes. First, it provides a common point of reference for staff working on PCSI diseases. Specifically, this document will be shared with staff and can be provided to new hires, when appropriate, as part of an orientation to the Division of Disease Control. Second, delineating what is currently permissible, particularly with the recent change in the HIV law, serves as opportunity for programs to think through additional data sharing needs. The PCSI Steering Committee⁵² and PCSI Data Advisory Committee were given the chance to review the report and provide feedback. In doing so, several data sharing issues were raised with the General Counsel's office which may lead to enhanced data sharing. Third, the current challenges posed by the STD law are being addressed by legislative proposals;

these discussions highlighted several other aspects of the law that are out of date. Finally, given the move to electronic reporting and electronic surveillance registries, particularly the implementation of Maven for all PCSI diseases, except HIV, there is opportunity for greater data sharing while still protecting the confidentiality of those whose names are in DOHMH registries. This means that the Division of Information & Information Technology (DIIT) works together with the disease programs and the General Counsel's Office to ensure that access to data complies with the law and internal confidentiality/security policies as well as CDC guidelines.⁵³ With technology, access controls can be tightly monitored, so that only the minimum necessary data are shared, and only those who need access to specific data are granted that access. Additional controls, such as regular audits of usage, can also support the protection of confidential data, while allowing the data to be used to support public health. Overall, this report serves as a case study of legal challenges to data sharing and provides important lessons for other jurisdictions implementing PCSI and seeking to increase data sharing.

Appendix A

Federal Laws Governing Disclosure of Protected Health Information

HIPAA is the federal law governing use and disclosure of medical records by “covered entities,” and as such does not apply to surveillance data.⁵⁴ HIPAA rules regarding disclosure only apply to entities “covered” under the act, which is defined to include health plans, health care clearinghouses, and health care providers who submit health information in electronic form in connection with a transaction under HIPAA.⁵⁵ The surveillance groups for the four disease areas are not considered to be involved in “health care” but rather “public health activities,” which is not within the definition of a HIPAA covered entity. Therefore, any disclosures made by one surveillance group to another are not activities covered by HIPAA.

Most physicians and clinics that disclose disease information to DOHMH are presumably “covered” health care providers under HIPAA, but disclosure to DOHMH is still permitted under two of HIPAA’s exceptions to confidentiality. HIPAA allows disclosure without the identified individual’s consent for public health activities, including disclosures to public health authorities for surveillance purposes.⁵⁶ Additionally, physicians are required by state and or local law to report cases of certain diseases to health authorities.⁵⁷ HIPAA also allows disclosure without consent if the disclosure is mandated by law.⁵⁸

Therefore under federal law, there are no regulations for disclosures between DOHMH surveillance groups, and disclosures by health care providers to DOHMH are permitted if it is made for surveillance purposes.

Appendix B

New York City Health Code § 11.11

Confidentiality of reports and records.

(a)(1) Epidemiological and surveillance reports and records of cases, contacts, carriers, suspect cases or suspect contacts of diseases and conditions of public health interest that are reported to the Department, including but not limited to additional information it may obtain, develop or prepare in the course of an epidemiological investigation, shall be confidential and shall not be subject to inspection by persons other than authorized personnel or agents of the Department or by the State Department of Health pursuant to the State Sanitary Code. The disclosure of such reports, records or information shall not be compelled. No individual's medical or individually identifiable information shall be disclosed from any epidemiological report or record, and no disclosure thereof may be compelled, regarding any individual who is the subject of, or identified in, such a report, or regarding an individual or entity that has made such a report.

(2) Epidemiological or surveillance information that is disseminated as aggregated statistical data shall be prepared as determined by the Department in a manner that does not reasonably enable re-identification of any person whose personal health or individually identifiable information is contained in such data.

(b) Notwithstanding subdivision (a) hereof, to the extent permissible under applicable law and in accordance with the provisions of § 3.25 of this Code, the person to whom any such epidemiological and surveillance report or record relates, or in the case of a minor or incompetent such person's parent, legal guardian or custodial guardian, may sign a written consent authorizing the Commissioner to disclose such person's own patient information or records of diagnosis or treatment. The consensual disclosure of such information shall only be made to the person to whom the information relates, or to such person's current treating medical provider, or to a court upon receipt of such a written consent and a court order from that court. A disclosure pursuant to this subdivision shall not include the identity of persons who reported the case, investigative or epidemiological information related to the case or the identities and epidemiologic, surveillance and laboratory information on the person's contacts or other suspect or confirmed cases, contacts or carriers associated with the same epidemiologic investigation.

(c) Subdivisions (a) and (b) of this section shall not prevent the Commissioner or authorized personnel of the Department from furnishing what the Department determines to be appropriate information to a physician or institution providing examination or treatment to a person suspected of or affected with a disease or condition of public health interest, to an agency approved by the Department for prevention, treatment or social service, or to any person when necessary for the protection of public health. Only the minimum information necessary for the intended purpose shall be disclosed. A person, institution or agency to whom such information is furnished or to whom access to records has been given shall not divulge any part thereof so as to disclose the identity of the person to whom such information or record relates, except insofar as such disclosure is

necessary for the treatment of a case or carrier or for the protection of the health of others.

(d)(1) Information contained in the immunization registry created pursuant to § 11.07 of this Article and the children's blood lead registry established pursuant to § 11.09 of this Article shall be confidential and not subject to inspection by persons other than authorized personnel or agents of the Department and persons or agencies authorized herein. The Department may disclose information contained in said immunization registry in accordance with the provisions of § 2168 of the New York State Public Health Law, and the regulations promulgated pursuant thereto. Information contained in the children's blood lead registry may be disclosed and the Department may permit access to such information by a person, authorized by law to administer or order a blood test, who is treating or testing the individual to whom said information relates, or to a public health agency for the protection of health. The Department may also disclose what it considers appropriate and necessary information from such immunization or children's blood lead registries to a person or agency concerned with immunization or blood lead testing of children authorized by the Department when (i) such person or agency provides sufficient identifying information satisfactory to the Department to identify the individual to whom such information relates and (ii) such disclosure is in the best interests of such individual and, in the case of a child, his or her family, or will contribute to the protection of the public health. Notwithstanding the foregoing, the person to whom any immunization or blood lead test record relates, or his or her custodial parent, guardian, or other person in parental or custodial relation to such person, may, by signing a written consent, authorize the Commissioner to disclose such record.

(2) A person, institution or agency to whom such immunization or blood lead registry information is furnished or to whom access to records or information has been given, shall not divulge any part thereof so as to disclose the identity of the person to whom such information or record relates, except insofar as such disclosure is necessary for the protection of the health of the person or other person.

HISTORICAL NOTE

Section repealed and added City Record Sept. 25, 2008 eff. Feb. 1, 2009 per City Record notice. [See Vol. 8 Statements of Basis and Purpose No. 77]

References

¹ Roush, S., Birkhead, G., Koo, D., Cobb, A., Fleming, D. Mandatory Reporting of Diseases and Conditions by Health Care Professionals and Laboratories. *JAMA*. 1999; 281:164-166., *See, e.g.*, 10 CRR-NY § 63.7

² Surveillance is the systematic collection and monitoring of data on specific disease collected by the DOHMH through reports on individual cases from medical providers and laboratories. Surveillance data are housed in registries, which are disease-specific databases of case information.

³ Although the sharing of surveillance data with outside entities such as medical providers is also covered by State and City laws, this type of data sharing is beyond the scope of this paper and is not addressed here.

⁴ U.S. Census Bureau <<http://quickfacts.census.gov/qfd/states/36/3651000.html>>

⁵ U.S. Census Bureau <<http://quickfacts.census.gov/qfd/states/36/3651000.html>>

⁶ The NYC Health Code defines “individually identifiable information” as “any information or data which by itself or in combination with any other publically available information could, in the opinion of the Department, be used to identify a particular individual. 24 RCNY 3.25. *See also*, personally identifiable information is defined as: “any information about an individual maintained by an agency, including (1) any information that can be used to distinguish or trace an individual’s identity, such as name, social security number, date and place of birth, mother’s maiden name, or biometric records; and (2) any other information that is linked or linkable to an individual, such as medical, educational, financial, and employment information.” GAO Report 08-536, *Privacy: Alternatives Exist for Enhancing Protection of Personally Identifiable Information*, May 2008, <<http://www.gao.gov/new.items/d08536.pdf>>

⁷ 45 CFR 164.512(b)

⁸ N.Y. Pub. Health Law § 2102 (McKinney 1953).

⁹ 10 CRR-NY § 2.12

¹⁰ Frieden, T., Lerner, B., Rutherford, B. Lessons from the 1800s: tuberculosis control in the new millennium. *The Lancet*, 2000; 355: 1088-1092.

¹¹ Comm. on Pub. Health of the New York Acad. of Med., Prevention of Viral Hepatitis. *Bull. N.Y. Acad. Med.* 1957;33:128-131.

<<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1806082/pdf/bullnyacadmed00371-0064.pdf>>

¹² Biggs, H. Venereal Diseases: The Attitude of the Department of Health in Relation Thereto. *New York Medical Journal*, 96; 1913: 1009-1012, at 1011.

¹³ There is no NYC specific law regulating HIV data.

¹⁴ 10 CRR-NY § 63.4 (1989)

¹⁵ Biggs, H. Venereal Diseases, at 1011.

¹⁶ 24 RCNY § 11.03

¹⁷ 10 CRR-NY § 2.1 & 23.3 (1983)

¹⁸ 24 RCNY § 11.03; 10 CRR-NY § 2.1 (1963)

¹⁹ N.Y. Pub. Health Law § 2221 (McKinney 1953)

²⁰ 24 RCNY § 11.21 (1993) (originally § 11.47, published 1991)

²¹ 24 RCNY § 11.21(a)(2)-(4)

²² NY Pub. Health Law §§ 2225-6 (1953); 24 RCNY § 11.21

²³ 10 CRR-NY § 2.1, 2.10 (1971); N.Y. Pub. Health Law §§ 2101-05 (1953)

²⁴ 24 RCNY § 11.03

²⁵ 10 CRR-NY § 63.4

²⁶ 1998 N.Y. Sess. Laws 163 (McKinney); N.Y. Pub. Health Law § 2130 (McKinney 1998).

²⁷ *Id.*

- ²⁸ Smith, L. Bureau of HIV/AIDS Epidemiology, N.Y. State Dep't of Health, HIV/AIDS Epidemiology in New York State, 2010 at 6. <http://www.amc.edu/PATIENT/services/HIV/documents/Smith_6-3_Updated_Print.pdf>
- ²⁹ City of New York Dep't of Health & Mental Hygiene, Agreement Relating to Public Health Law Article 21, Title III: HIV Reporting and Partner Notification (Dec. 17, 2003) (on file with DOHMH).
- ³⁰ 1998 N.Y. Sess. Laws 163
- ³¹ N.Y. Pub. Health Law § 2135 (McKinney 1998).
- ³² *Id.* at (c).
- ³³ *Id.*
- ³⁴ <<http://w3.health.state.ny.us/dbspace/NYCRR10.nsf/56cf2e25d626f9f785256538006c3ed7/552eb22edc01f9fe8525706000457bfd?OpenDocument&Highlight=0,hiv>>
- ³⁵ *Id.*
- ³⁶ While redisclosure to providers is an important issue, it is outside the scope of this current paper.
- ³⁷ N.Y. Pub. Health Law § 2306 (McKinney 1953).
- ³⁸ The other exceptions relate to when STD reports can be released pursuant to court order. N.Y. Pub. Health Law § 2306
- ³⁹ Grattan v. People, 65 N.Y.2d 243 (1985)
- ⁴⁰ 24 RCNY § 11.11
- ⁴¹ *Id.* at (c).
- ⁴² *Id.*
- ⁴³ 10 CRR-NY § 2.32 (1973); 24 RCNY § 11.11
- ⁴⁴ 24 RCNY § 11.11(a)(1)
- ⁴⁵ N.Y. Pub. Health Law § 2221 (McKinney 1953)
- ⁴⁶ 10 CRR-NY § 2.17
- ⁴⁷ *Id.*
- ⁴⁸ N.Y. Pub. Health Law § 18 (McKinney 1986); 24 RCNY § 11.11(a)(1)
- ⁴⁹ 24 RCNY § 11.11(c)
- ⁵⁰ *Id.* While surveillance data is not covered by HIPAA standards, HIPAA security standards are frequently used as a guide.
- ⁵¹ 45 C.F.R. § 164.502(b)
- ⁵² The PCSI Steering Committee is comprised of the Assistant Commissioners of the Division of Disease Control, Chief Privacy Officer, and other senior level staff.
- ⁵³ Centers for Disease Control and Prevention. Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action. Atlanta (GA): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2011.
- ⁵⁴ 45 C.F.R. §§ 160, 162, 164
- ⁵⁵ 45 C.F.R. § 160.103
- ⁵⁶ 45 C.F.R. § 164.512(b)(1)(i)
- ⁵⁷ *See, e.g.* 24 RCNY § 11.21(a)(1)
- ⁵⁸ 45 C.F.R. § 164.512(a)(1)

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