

INFORMATIONAL PRIVACY PROTECTIONS: DO STATE LAWS OFFER PUBLIC
HEALTH LEADERS THE FLEXIBILITY THEY NEED?

Jean C. O'Connor

A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in
partial fulfillment of the requirements for the degree of Doctor of Public Health in the
Department of Health Policy and Management in the School of Public Health.

Chapel Hill
2009

Approved by:

Thomas Ricketts

Ali Khan

Gene Matthews

Jonathan Oberlander

Pam Silberman

© 2009
Jean C. O'Connor
ALL RIGHTS RESERVED

Abstract
Jean C. O'Connor
INFORMATIONAL PRIVACY PROTECTIONS: DO STATE LAWS OFFER PUBLIC
HEALTH LEADERS THE FLEXIBILITY THEY NEED?
(Under the direction of Thomas C. Ricketts, III, Ph.D.)

Some scholars have argued that there is a tension between privacy and the public's health. This study explores that tension in a contemporary context by examining the current status of informational privacy laws and by inquiring whether current state statutes are adequate to protect the privacy of public health information during a time when terrorism and globalization appears to be forcing a choice between liberty and security. Two methods were used in this study: 1) a point-in-time policy analysis of state public health privacy laws using criteria previously established by a panel of public health privacy experts; and 2) key informant interviews with federal officials, national organizations, and state health officials and privacy officers. The findings suggested that despite much attention over the past decade, including the development of model state statutes, few states have laws that comprehensively address both public health privacy and disclosure. Both federal and state officials viewed privacy protections for health-related data as important and recognized the tension between privacy interests and the need to share information. Sociopolitical factors and interest groups have driven change in the laws of some states while other states have made few changes to their laws over the past decade. State officials suggested that state public health privacy statutes, where they exist at all, are generally adequate for state public health practice.

However, both state and federal officials suggested state laws are sometimes barriers to the inter-jurisdictional sharing of information and may present challenges in the future as federal policies promoting the electronic sharing of health-related information are implemented. And, federal and state key informants acknowledged that the lack of uniformity in laws and practices related to the acquisition, use, and storage of public health information across states is a source of confusion for individuals, health care providers, and government agencies. A universal framework for protecting the privacy of public health information may be useful or necessary and with health reform imminent, the development of electronic medical records, and a pandemic of a novel influenza virus, there may be a window of opportunity to develop policies supporting such a framework.

To Joe and Laura.

ACKNOWLEDGEMENTS

Although I owe more people a debt of gratitude than I can name here, I would be remiss if I did not specifically acknowledge the many people who supported me in this effort along the way, including my family, my committee, and the very wise individuals at UNC who have worked so hard to make it possible for a lucky few of us to both work in public health and go to school at such a fine institution. I also wish to acknowledge my Emory students whose enthusiasm for using policy to improve health has been more valuable than any degree, my friends at Emory and CDC, and my Dr.P.H. cohort from whom I learned so much. Finally, I wish to thank my colleagues in the public health law community—those who practice law and those who practice public health—for sharing their insights, knowledge, friendship, enthusiasm, and dedication to the public’s health and for always facing the challenges of our work with great humor.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	v
LIST OF TABLES	viii
INTRODUCTION	9
<i>Background</i>	3
<i>Research Questions</i>	8
<i>Conceptual and Methodological Approaches</i>	8
<i>Significance</i>	9
LITERATURE REVIEW	10
<i>How Public Health, Surveillance, Investigations, and Interventions are Carried Out</i>	10
<i>The “Liberty-Security Trade-Off”</i>	16
<i>A Post Sept 11 Federal Preparedness Policy Paradigm</i>	19
<i>Current State and Federal Privacy Law</i>	23
<i>Initiatives to Address State Public Health Privacy Issues</i>	27
STUDY DESIGN AND METHODOLOGY	30
<i>Conceptual Approach</i>	31
<i>Study Design</i>	32
Method 1: Statutory Analysis	32
Method 2: Key Informant Interviews	38
<i>Limitations of this Study</i>	45

RESULTS	48
<i>Comparative State Policy Analysis</i>	48
<i>Key Informant Interviews</i>	59
<i>Summary of Results</i>	89
PLAN FOR CHANGE.....	94
<i>Components of a National Framework</i>	95
<i>Development of the Framework</i>	97
<i>Opportunities for Implementation and Need for Policy Change</i>	100
<i>Future Research Opportunities and Evaluating Implementation of the Framework</i>	102
DISCUSSION	103
APPENDIX A. KEY INFORMANT INTERVIEW RECRUITMENT EMAIL.....	110
APPENDIX B. STATE KEY INFORMANT INTERVIEW DISCUSSION GUIDE	111
APPENDIX C. FEDERAL KEY INFORMANT INTERVIEW DISCUSSION GUIDE....	112
APPENDIX D. KEY INFORMANT INTERVIEW TELEPHONE CONSENT SCRIPT..	113
APPENDIX E. STATUTORY ANALYSIS.....	115
REFERENCES	118

LIST OF TABLES

Table 1. Preliminary list of privacy protections and information sharing Provisions 37

Table 2. Key informant interviewees by profession 42

Table 3. States with general privacy, use and disclosure, and exceptionalism provisions 52

Table 4. States with selected MSHPA and MESHPA provisions 54

INTRODUCTION

In 1890, United States Supreme Court Justice Louis D. Brandies called it the most important and comprehensive right—“the right to be let alone.”¹ This right of privacy, perhaps better described as a right of autonomy or self-determination, has ethical, human rights, and legal dimensions. Privacy has its legal roots in the United States in the language of the Constitution, which states that “no person shall be deprived of life, liberty, or property without due process of law.”² There are at least two dimensions to the right of privacy. The first type, known as decisional privacy, is a physical right of self-determination and freedom from government interference reserved for fundamental issues such as child bearing and rearing, interstate travel, marriage, and procreation. The second type of privacy right, often called informational privacy, is the freedom to control the distribution of personal information about one’s self.

Privacy advocates might say that the protection of these ideals is the very essence of the United States. But, like most rights, the right to privacy is not absolute. The right to privacy has been interpreted by the United States Supreme Court as one that must necessarily be balanced with the needs of the public. This tension between private rights, particularly the right of privacy, and the public good is nowhere more acutely felt than in public health. Privacy rights can and must be curtailed in some circumstances to ensure the public’s health.

As the United States Supreme Court so elegantly pointed out in the famous 1905 case known as *Jacobson v. Massachusetts* involving compulsory vaccination for smallpox—

*The liberty secured by the Constitution of the United States to every person within its jurisdiction does not import an absolute right in each person to be, at all times and in all circumstances, wholly freed from restraint. There are manifold restraints to which every person is necessarily subject for the common good. On any other basis organized society could not exist with safety to its members.*³

If too great a number of people refuse vaccination for a communicable disease, if partners are not notified of their exposure to a sexually transmitted infection, or if a dangerous public place, such as a restaurant serving contaminated food were not closed, the public would suffer the health, economic, and social consequences of the spread of disease. Because it touches almost every aspect of public health practice in some way, legal scholar Lawrence O. Gostin and many other scholars have called the relationship between privacy and the public good *the* fundamental tension in public health.⁴ However, public health is not built solely on the diminution of privacy rights; public health and privacy can also have a synergist relationship. Trust between affected populations and government officials is critical to public health practice and is developed or sustained, in part, through respect of privacy and avoidance of unnecessary disclosure or stigmatization.

The detection and mitigation of diseases and environmental conditions to reduce the impact on human health have long been recognized as possibly the most critical function of public health practice.⁵ The tension, though, between this need and privacy, especially informational privacy, has been particularly acute since September 11, 2001, the anthrax attacks in the fall of 2001, Hurricane Katrina, and the development of information technology that makes data available rapidly. As a consequence, policy entrepreneurs, particularly at the federal level, have promoted, through laws, policies, and practices, the idea

that widespread exchange of public health information is needed to speed the detection of, and response to, public health exigencies and bioterrorism.⁶ These policy entrepreneurs have acted on the premise that today's global society with its rapid exchange of people, trade, and information,⁷ the threat of bioterrorism, and changing global demographics means that the rapid flow of public health information is essential to safety and health. They have argued that such information can help to detect, respond to, and mitigate potential harms to the public's health, such as emerging infectious diseases and environmental hazards, whether naturally-occurring or intentional⁸ and flatten the epidemiology curve associated with the outbreak or event.

Critics of recent federal policy developments have suggested this shift toward an emphasis on the more rapid sharing of information to facilitate detection and response to public health events has been at the expense of privacy and possibly even the broader purpose of public health to create the conditions that allow people to be healthy. Others wary of this emerging policy approach have suggested that the choice between liberty and security is a false one and that we need not sacrifice privacy or security for information flow. With this debate as context, this dissertation explores the practical aspects of the balance between privacy and public health interests, seeking to understand the current status of state public health privacy laws and practices and the perspectives of state and federal health officials related to that balance.

Background

Today in the United States, the responsibility for the public's health is shared at the local, state, and federal levels⁹ and is reflected in a complex set of public health laws,

policies, and practices.¹⁰ Primary legal authority for the reporting and investigation of public health events and to protect and promote the public's health is reserved to the states under the 10th amendment of the Constitution.^{5,11} Some of the first public health laws in the United States were state laws requiring the reporting of vital statistics, such as births and deaths, and those relating to the detection and mitigation of infectious diseases such as smallpox through the inspection and quarantine of maritime vessels.¹²

As articulated under section 301(a) of the Public Health Service Act,¹³ the United States Department of Health and Human Services (HHS) and its agencies, particularly the Centers for Disease Control and Prevention (CDC), serve largely in a technical assistance and financing role for the states and responding, in practice, only when requested by state or local authorities or in a national event. HHS and other federal agencies conduct very little primary public health data collection; information about specific diseases and conditions is collected directly by the federal government only in very limited circumstances, such as where foreign or interstate travel or commerce may be affected or in multi-state outbreaks of disease. Public health interventions are carried out mainly at the state and local level. The relationship between the states and federal government in much of public health, therefore, is one in which the states generally retain most of the authority and responsibility for public health but rely on the extensive financial and technical resources of the federal government for support. The federal government and CDC especially, in turn, generally rely on the cooperation of the states to report and intervene in most public health events and request assistance when needed.

This means that states and state public health laws are extremely important to public health practice. However, state public health laws, many of which were not amended by state

legislatures for a better part of the 20th Century as infectious diseases became less predominant, have been called antiquated and outdated by some.¹⁴ Research has suggested that, depending on the jurisdiction, the diseases and conditions that are reportable vary, the persons and organizations required to report cases or suspected cases differ, privacy protections for the information reported to public health are nuanced, and rules for the sharing of information and protecting records have a range of exceptions.^{5,10} The lack of uniformity in state laws is not necessarily undesirable when it is an expression of state autonomy or leads to innovation and new approaches. However, it can sometimes be problematic from a national perspective when it leads to significant gaps in authorities or programs within or across states.

Over the past decade, the federal government has made a number of attempts to address various aspects of the tension between sharing public health information and protecting privacy. Model state laws have been developed as a means to promote a more national uniform approach. In 1999, around the time the Privacy Rule of the Health Insurance Portability and Accountability Act (HIPAA) was being considered by Congress, the Model State Health Privacy Act (MSHPA) was drafted by scholars at Georgetown and Johns Hopkins Universities as a means to disseminate ideas about ways to update state statutes related to the protection of the privacy of health-related information. The MSHPA contains detailed language about the appropriate acquisition and use of public health information, terms for when disclosure of public health information is appropriate, and privacy infrastructure to be put in place by state health departments, and penalties for non-compliance.

After the events in the fall of 2001 raised questions about the ability of government to detect and respond to public health emergencies, the same Georgetown and Hopkins scholars that led the development of the MSHPA developed a model law known as the Model State Emergency Health Powers Act (MSEHPA). The MSEHPA contains provisions intended to enhance the capacity of the states to collect and share public health information in emergencies,¹⁵ although critics have argued that those provisions undermine privacy interests by providing the chief executive of a state too much autonomy in deciding what information can be collected and how it can be used. The MSEHPA set out in detail provisions and ideas that would enhance or facilitate the detection of, and response to, a public health emergency or event. The Act was promoted by CDC as a benchmark against which states could measure if their laws met certain CDC preparedness objectives. The implementation of some provisions from the MSEHPA was encouraged or required for states applying for CDC public health preparedness grant funds.¹⁵

In addition, as part of the shifting federal policy focus, Congress and the Bush Administration sought to improve the timeliness and sharing of some types of public health data and information in order to detect and respond to domestic and international infectious disease outbreaks and other public health emergencies through the Pandemic and All-Hazards Preparedness Act of 2006 (PAHPA), Homeland Security Presidential Directive-21 (HSPD-21), and other federal laws, policies, and programs. PAHPA requires HHS to, among other things, ensure the establishment of “a near-real-time electronic nationwide public health situational [sic] awareness capability,” or “system of systems” built on existing state surveillance capabilities.¹⁶ HSPD-21, issued by President Bush in 2007, mirrors the language in PAHPA, calling on HHS to build the network of systems using existing Federal, State, and

local surveillance systems to detect public health emergencies.¹⁷ Both HSPD-21 and PAHPA, in other words, could be interpreted as having significant implications for the extent and nature of public health information exchange.

Although both PAHPA and HSPD-21 recognize in broad, sweeping terms the need to protect the privacy of identifying data and both are presumably predicated on the inclusion of state public health data in the network or systems, the policies themselves say nothing about how conflicting privacy protections across jurisdictions will be reconciled. They also say nothing about how the goals will be achieved under an existing set of federal laws that govern how some types of public health information are shared and with whom, including the Federal Privacy Act,¹⁸ the Health Insurance Portability and Accountability Act (HIPAA),¹⁹ and the 14th Amendment to the United States Constitution.²⁰

The drafters of the MSHPA and MSEHPA have broadly tracked examples of implementation. However, changes to state laws made as a result of the two model acts or driven by PAHPA, HSPD-21, or other factors, have only been minimally studied. The variation in the laws of the 50 states governing how public health information is collected, used, and protected may also have important implications for achieving national objectives to improve surveillance and a nationwide capability that enables awareness of disease events as the events unfold.²¹ However, no analysis of state laws assessing the extent to which states may share public health information or to what degree that information must be protected exist. And, a search of the literature did not reveal any analysis of the current attitudes of public health leaders on the need for balance between privacy rights and disclosure of information for public health preparedness purposes.

Research Questions

Given this, it is reasonable to ask to how state laws protect the privacy of public health information and whether those existing laws provide sufficient practical guidance for to public health practitioners. This dissertation outlines an approach to addressing these questions and extends the understanding of the contexts that have created the current policy environment. In addition to framing this understanding in terms of the federal policy context (i.e., federal and Constitutional civil liberties and privacy protections), this study will explain the extent to which enacted state laws balance the protection of the privacy of public health information with the need to share public health information by:

- 1) Describing state laws and policies enacted as of January 1, 2009 that govern the privacy protections within each state's public health system and between each state and the federal government; and
- 2) Assessing the understanding and perspectives of federal and state officials engaged in the implementation efforts related to HSPD-21 and PAHPA regarding state public health information sharing and privacy laws.

Conceptual and Methodological Approaches

This study is a policy study. A policy study describes policies, explains their existence, and evaluates them.²² One type of policy study, policy evaluation, has emerged in the past decade as a means to assess factors in the broader social environment that affect group or individual behavior. Evaluations identify, clarify, and apply criteria to determine the efficacy or effectiveness of a particular approach or technique.²³ Policy evaluation studies

have been used extensively in public health practice to measure, or evaluate, the practical effectiveness of policies at the state or federal levels to achieve a particular purpose.²⁴ This study is descriptive in nature and does not test a theory. However, I have drawn from theories that predict or explain the formulation of new public policies, such as Kingdon's Three Streams Model,²⁵ in the final section of this document that outlines a plan for change. The idea that law and policy are one of many factors influencing the social environment that influences health, drawn from the Socio-Ecological Model, is also reflected in this dissertation.

Significance

The findings from this study have implications for how the public health system collects and shares data and information to perform its essential functions, especially emergency response and disease surveillance. The findings may also have implications for the call by some legal scholars over the past decade for a federal law that will protect the privacy of public health information similar to the way HIPAA covers certain health care-related information. More specifically, this study also has the potential to inform efforts by CDC and its partners around broader efforts to encourage "legal preparedness" for responding to public health threats. This study may also help to inform how federalism is addressed in meeting the surveillance requirements in the International Health Regulations.^{26,27} Finally, the findings from this study may have implications for the implementation of PAHPA or HSPD-21 and could be incorporated into the federal implementation plans of those activities. A change in federal leadership often coincides with a period of agenda setting around federal policies, and it is intended that the findings from this study inform the direction in public health surveillance data policies.

LITERATURE REVIEW

How Public Health, Surveillance, Investigations, and Interventions are Carried Out

Community engagement is the primary means by which public health is practiced. The Institute of Medicine has stated that the three core mechanisms by which public health achieves community engagement are: 1) assessing and monitoring the health of populations; 2) developing policies that improve health outcomes; and, 3) assuring the health of the public through access to preventive and acute health care.⁹ Assessment and monitoring of the population's health status is carried out in a variety of ways, including research, recording vital events (i.e., births and deaths) at the population level, and, perhaps most importantly, through the surveillance, investigation, and mitigation of conditions or events that impact the public's health. Public health surveillance is the ongoing systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation, and evaluation of public health practice.²⁸ The value of public health surveillance is closely linked to the timely dissemination of data and information about health events to those responsible for prevention and control.²⁸ The term "biosurveillance" is now also being used among federal officials to describe the collection and use of human, animal, and environmental health surveillance data and the translation of that data into information that can be rapidly acted upon by decision makers and emergency response personnel to protect human health.

Both traditional public health surveillance and biosurveillance are forms of disease surveillance. In the United States, disease surveillance is thought to have started in 1874 in Massachusetts with the weekly voluntary reporting by physicians of prevalent diseases. In 1893, the Quarantine Act authorized the United States Public Health Service to collect morbidity information from state and local public health authorities. Today, CDC operates the National Notifiable Diseases Surveillance System (NNDSS) along with tens, if not hundreds, of other major health-related surveillance systems, which remain largely disease-specific.²⁹ Disease surveillance is conducted for numerous reasons, primarily to assess the status of the public's health, define public health priorities, evaluate programs, and stimulate research.³⁰ Surveillance of public health conditions can also facilitate case detection, outbreak or problem detection, and provide early warning of infectious disease outbreaks, biological, or chemical terrorism and other public health emergencies.³¹ However, the usefulness of surveillance data varies with the disease and with the method by which the data are collected. If a condition is severe or newly emerging and primary prevention of the cause is possible, surveillance data collected about individual cases of disease can be useful.³² However, if the condition or disease cannot be prevented, has a minimal health impact, or is endemic, surveillance methods that focus on estimating the number of cases may be more appropriate. Early identification, reporting, isolation, and management can slow or stop the spread of communicable and emerging infectious diseases, when the right conditions exist (e.g., good population awareness, adequate health facilities, beliefs that support reporting, and adequate diagnostic techniques.)^{33, 34}

Other uses of data generated by public health surveillance activities include: informing decisions by health officials about when to use public health interventions,

estimating disease or injury impact or burden, explaining the natural history of a health condition, determining the geographic distribution and spread of illness, generating hypotheses, evaluating the effectiveness of prevention and control measures, and facilitating planning.³¹ Although data collection usually is driven by a need to identify human cases of infectious disease, public health or biosurveillance data can be gathered from a wide range of sources. These sources include: environmental monitoring systems, animals or vector monitoring systems, food safety systems, individuals, laboratories, medical records, administrative records, police records, and vital records (e.g., birth and death certificates). Each source has benefits and limitations.

There are at least five approaches to collecting public health or biosurveillance surveillance data: passive, active, sentinel, special systems, and statistical surveillance. These types of surveillance are not mutually exclusive. Passive surveillance involves reporting by clinical health care providers (or their animal or environmental health equivalents) when they diagnose a case that must be reported to the health department. Active surveillance implies an activity on the part of the health department, such as active outreach through telephone calls or visits, to encourage the reporting of cases of specific diseases.³⁵ Active surveillance is used to identify cases in a known outbreak, as a method of validation for passive reporting, and to seek out cases of diseases that have been targeted for eradication (e.g., smallpox and polio).³⁵ Sentinel surveillance is the collection of data about a particular disease from a part of the total population, usually a population at high risk, to identify trends.³⁵ Special surveillance systems, including syndromic surveillance systems, are those that are established for specific purposes to find out something about point or periodic prevalence of diseases or conditions that are generally otherwise not reportable to the health department.³⁵ For

example, where there was reason to believe the spread of an emerging infectious disease, such as human cases of avian influenza, might spread to a particular location, the health department might set up a temporary surveillance system looking only for that particular disease. Statistical surveillance approaches include analyzing data from public health-related or other sources, such as demographic surveys (e.g., the United States Census) to identify long-term trends in health conditions.³⁶ Statistical surveillance is used for conditions such as head injuries, which are difficult and expensive to count on a case-by-case basis. To estimate head injuries, CDC estimates the number of cases by state or nationally using a statistical sample of death records and a program established in a convenience sample of hospitals to enable more accurate estimates to be generated. Some combination of all five approaches to surveillance is needed within the public health system to identify and follow the spectrum of diseases and conditions, naturally occurring or intentionally caused, that can impact the public's health.³⁷

Overlapping surveillance approaches that vary depending on type of disease or human health hazard are necessary because monitoring the public's health is an imperfect art. Collecting health-related data across the local, state, federal, and international levels is enormously challenging. Data can be incomplete, underreported, and not timely. Multiple sources of data can allow for triangulation to identify significant findings. In the US, it is well known that health care providers significantly underreport cases of disease. This is caused by a number of factors, including a lack of training in the legal requirements and importance of disease reporting, perceptions regarding the importance of physician-patient privilege, belief that reporting responsibility falls elsewhere, and the lack of incentives for reporting.³⁸ Although surveillance systems do not need complete reporting to have value,

underreporting can distort trends, attributable risk estimates, and geographical distribution of cases. In addition, it can prevent the accurate assessment of potential benefits of control programs and prevent timely identification of disease outbreaks.³⁹ Untimely data can also inhibit the detection of outbreaks or use of surveillance system data.⁴⁰ For example, when the timeliness of the Nationally Notifiable Diseases Surveillance System (NNDSS) was evaluated, this federal system that holds voluntary state reports to CDC of particular diseases was found to have a time lag in receiving data from the states that ranged from 12 days for meningococcal disease to 40 days for pertussis. As a result, NNDSS data was found to be of limited use for the detection of, and response to, multistate outbreaks of infectious diseases.⁴⁰ Still NNDSS serves a different purpose; it provides a record of case counts for certain diseases and conditions.

When surveillance systems, whether formal or informal or at the state or federal level, do detect cases or clusters of usual disease, a public health investigation may be triggered.⁵ A public health investigation involves confirming the occurrence of an outbreak through active data and information gathering, identifying and characterizing cases of disease, and developing and testing hypotheses explaining the cases, and, finally, implementing control measures to inhibit the further spread of the disease or condition as needed.^{5, 41, 42} Depending on the authority of the public health officials in the jurisdiction, these control measures might involve fining or closing a business or facility that is the source of illness or contamination, requiring an individual to submit to further follow-up testing for a specific disease or condition, requiring an individual to modify their behavior, quarantine, isolation, or observing that the therapeutic intervention, such as a pharmaceutical regimen, is followed.

Taking effective measures can also at times mean the disclosure of the name of a person or group of persons exposed or at risk for a particular condition.

Because the primary legal authority for the protection and promotion of the public's health is reserved to the states under the 10th amendment of the United States Constitution, public health surveillance, investigations, and interventions generally take place at the state or local level.⁴³ The federal government does provide technical assistance to the states and controls significant financial resources that are distributed to conduct state public health activities under Article I, Section 8 of the Constitution.⁴⁴ Direct assistance from the federal government in these activities may be provided when requested by the states, when state or local public health capacity to respond is overwhelmed, or when international travelers, interstate commerce, or certain agents or diseases are involved, or when the Secretary of HHS determines that a public health emergency exists.^{45,46,47} The result is a complex and overlapping system of public health surveillance, investigation, and response that is fragmented.¹⁰

Although all states have some sort of broad statutory language that require some reporting of diseases of public health significance, the specific diseases and conditions collected by states are not uniform.⁴⁸ There is no single definitive source on state disease or condition reporting requirements. The Council of State and Territorial Epidemiologists (CSTE) sponsors a list of suggested reportable conditions by state that is the best available resource.⁴⁹ Previous efforts to develop or maintain such a list or database have been undertaken on an as needed basis. In 1999, a survey of state and territorial epidemiologists was conducted to assess the states' public health reporting requirements. The researchers found that only 19 of the 58 diseases and conditions on the list for national surveillance were

actually reportable in each of the 53 responding states and territories. In 2002, CDC released a study of the disease reporting laws of 54 jurisdictions to determine how many had laws mandating the reporting of critical biological agents disease. The study showed deficiencies in immediate reporting requirements for category A agents, such as anthrax, botulism, plague, smallpox and tularemia.⁵⁰ Prior to that, according to a 1990 CDC report, a compilation of disease reporting requirements in the United States was last published by the United States Public Health Service in 1933 and 1944.⁵¹ There is also no list of the surveillance systems maintained by states (or the federal government) nor is there a national list or registry of public health interventions taken by health officials.

The “Liberty-Security Trade-Off”

While data and information sharing to protect the public’s health is legitimately necessary in circumstances, it is not always clear how much information is needed, by whom, and for what purposes.⁵² On the one hand, careful monitoring by modern surveillance systems and sharing information within public health across levels of government supported the early detection of new and resurgent infectious disease threats, including well known examples such Severe Acute Respiratory Syndrome (SARS)⁵³ and the early detection of food-borne outbreaks.⁵⁴ Effective public health emergency planning, prevention, and response can promote the communication and the sharing of information between various entities, ranging from public health authorities and health care workers to national security and law enforcement officials to the judiciary.^{55,56} On the other hand, sharing too much information with law enforcement, for example, has the potential to undermine the public’s trust that public health will protect health information, probably the most sensitive of any

information about an individual, and use it only for the purpose for which it was collected.⁵⁷ Unauthorized disclosure of health information can result in stigma, loss of health care, employment discrimination for affected persons.⁵⁸

Scholars argued that this tension between the disclosure of public health data and information and the privacy and liberty interests of individuals and communities,⁵⁹ referred to by some as the “liberty-security trade-off,” is one of the most fundamental tensions in public health.^{4, 60} While that tension has always been present to some extent in civil societies, since John Stuart Mill’s *On Liberty* and Warren and Brandeis’s famous article “The Right to Privacy” were published, American has placed increasing value on liberty interests and protecting the privacy interests of citizens from government intrusion.^{1, 57, 61} The emphasis placed on those values has conflicted over the past 10 years with a perceived renewed threat of bioterrorism that sometimes appears to justify surveillance of all types and with the development of information technology that makes it easier than ever to collect and share information previously protected by relative obscurity.⁶²

Informational privacy is about competing interests. It is about the “the claim of individuals, groups, or institutions to determine for themselves when, how and to what extent information about them is communicated to others.”^{63, 64} Privacy and public health advocates disagree over the extent to which the public health need for data should override the informational privacy rights of individuals.⁶⁵ While privacy protections may help to promote the public’s health by encouraging individuals to fully utilize health services, they can also simultaneously be used to prevent data sharing that could improve the public’s health.^{66, 67, 68} For example, spatially-based methods of public health surveillance that use precise patient

locations to detect outbreaks yield more accurate results than those that do not use exact patient location. Those methods, however, also pose a greater risk to privacy.^{69,70}

According to legal scholar Larry Gostin, “significant levels of privacy cannot realistically be achieved within the current health information infrastructure,” leaving public health with a “hard choice” about whether to limit what information is collected in the name of privacy or collect the information in the name of public health.⁵⁷ Some privacy advocates argue that public health surveillance inhibits the clinical freedom of health care providers by requiring providers to interact with health departments. They also contend that public health surveillance limits patient autonomy and disproportionately affects the poor and minorities.⁷¹ These advocates argue that health care providers should have the ability to decide when, if at all, to report a case of a disease or illness, depending on what the provider feels is in the best interest of the patients. They also believe that patient autonomy is threatened by a loss of control over personal information sent by a provider to a health department. And they suggest that the poor and minorities, who are disproportionately burdened by disease and poor health conditions, are most likely to have their health conditions reported to the health department.

Often without directly refuting these arguments, public health advocates argue that privacy, clinical medicine, and public health practice are, or can be, synergistic. Public health advocates contend that only by clinical providers making the public health system aware of cases and conditions and allowing experts in the field of population-based interventions to become involved in cases of disease, can the health of all people be adequately protected. The parable of the “tragedy of the commons,” in which a common pasture in a village is destroyed when no common governance structure exists to limit the self-interests of

individuals, is often invoked as an analogy to explain the importance of government in making difficult choices about limiting privacy interests or private rights to promote the public's health.⁷² Public health advocates believe that privacy protections, if granted in degree and limited only when absolutely necessary, breed trust. In turn, they argue, this trust enables public health.

Debate continues as to whether risks to privacy, especially the privacy of vulnerable and special populations, “justify less accurate but still adequate reporting systems.”⁷³ Case reporting has been used as a tool for centuries within public health practice to control sexually transmitted infections. However, in the past half century, fear of stigma and discrimination led to a decade of very public and passionate debate in the United States between public health advocates, affected populations, and civil libertarians over the possibility of named reporting of HIV cases.^{73, 74} Where case reporting does take place for certain diseases, privacy advocates have even challenged the sharing of that data within the same agency. Anecdotal reports have suggested that linking HIV and TB data is prohibited in some jurisdictions. Inter-jurisdictional data sharing is even more controversial, with occupational and environmental surveillance professionals, reportedly expressing concerns about data sharing across governments even for public health purposes.⁷⁵ Very little evidence is available, however, about the prevalence of attitudes or concerns about privacy and public health among the public or public health leaders.

A Post Sept 11 Federal Preparedness Policy Paradigm

Despite the challenges, for decades state and local public health departments have collected a vast array of important and useful data and information. Public health has

exchanged that information with federal health officials, clinical providers, and others to carry out the functions of the public health system.⁷⁵ However, the events in the Fall of 2001, including the terrorist attacks on the World Trade Center in New York and the anthrax attack on buildings and individuals in Florida and the Washington, D.C. area, led many people and policy makers to conclude that early warnings through better surveillance and faster response could be achieved by putting the vast array of information collected at the state and local level into the hands of more people at all levels of government.⁷⁶ This paradigm was reinforced by the public health crises associated with the rapid global spread of Severe Acute Respiratory Syndrome (SARS) in 2003 and Hurricane Katrina in 2005. Over the same time period, wireless technologies became broadly accessible to the public and government, raising expectations that information is always available and messages can be widely disseminated at any time.

While most public health practitioners agree that some measure of information sharing is intuitively important in some circumstances, little empirical evidence is available on the value of sharing personally identifiable information held by health departments, especially sharing that information outside public health agencies. But exigencies and fear, which are often the motivating factor for rapid policy development, resulted in a major infusion of federal resources and focus on establishing methods and mechanisms for widespread mandates for sharing health-related information and other information that might detect or prevent terrorism or disasters.⁷⁶ This shift was expressed in several important federal policy initiatives. The Pandemic and All-Hazards Preparedness Act of 2006 (PAHPA), passed in 2006, includes a provision that amends the Public Health Service Act. The provision calls for the enhancement of disease monitoring efforts and the sharing of the

data and information from those efforts across the United States at the state, local, tribal, territorial, and federal levels.⁷⁷ The Act further calls on the Secretary of HHS to establish, in collaboration with State, local, and tribal public health officials, “a near real-time electronic nationwide public health situational awareness capability through an interoperable network of systems to share data and information to enhance early detection of rapid response to, and management of, potentially catastrophic infectious disease outbreaks and other public health emergencies that originate domestically or abroad.” It requires that this network be built on or enhance existing State surveillance systems.

Mirroring the language in PAHPA, the executive policy document known as Homeland Security Presidential Directive-21 (HSPD-21), provides that HHS will build the network of systems using existing Federal, State, and local surveillance systems and to provide incentives to establish local surveillance systems where systems do not currently exist.¹⁷ HSPD-21, which was issued in 2007, provides for collaboration across HHS and other federal agencies to establish a plan to develop the network. HSPD-21 also sets forth other guiding principles for the development of the network, including the need for the network to be: flexible, timely, and comprehensive; protect individually identifiable data, and incorporate data into a nationally shared understanding of current bio-threats and events.

Interestingly, both PAHPA and HSPD-21 followed the establishment of another Homeland Security Presidential Directive, HSPD-10, which outlined the Executive Branch’s Biodefense Strategy for the 21st Century.⁷⁸ In HSPD-10, it was the Department of Homeland Security (DHS) rather than HHS that was called on to develop a nation-wide system that would permit early warning of a biological event. The transfer of this responsibility to HHS seems to reflect a changing understanding by policy makers of the respective roles of the two

agencies and the complexity of human health surveillance. In 2002, the Bush administration proposed to move several major bioterrorism programs, totaling more than 4 billion dollars and including the Strategic National Stockpile, from CDC to the Department of Homeland Security.⁷⁹ This was a significant departure from the previous recommendations of the United States Commission on National Security and the first of several policy actions by the Bush administration that signaled Homeland Security was the lead agency in any emergency response, including public health events such as pandemic influenza. HSPD-21, while possibly an anomaly, may represent a shift in thinking about the respective roles and responsibilities of Homeland Security and HHS in public health emergency response.

The idea that a shared understanding of public health is critical can also be found in other recent policies developed outside and inside the public health domain. In the final report of the National Commission on Terrorist Attacks Upon the United States, commonly known as the 9/11 Report, the Commission reflected on the need for government to draw on all relevant sources of information to protect the public, including public health information.⁸⁰ When the United States became a party to the revised International Health Regulations (IHR), the United States agreed to participate in a global system of information exchange to detect public health emergencies of international concern.^{81,82} The IHR is an international agreement that requires parties to develop the nation-wide surveillance capacity to detect, assess and report to the World Health Organization certain public health events and conditions, such as the recent outbreak of the novel H1N1 influenza virus.

Current State and Federal Privacy Law

The legal landscape around the right to informational privacy is complex. The United States Constitution, with its negative design that establishes limits on government interference rather than expressing a positive list of rights, offers a limited right to privacy but does not impart a broad expectation of informational privacy. The courts have found exceptions to the procedural and substantive due process rights imparted under the 5th and 14th amendments. These exceptions permit the collection and disclosure of personal information by the federal government and the states, respectively, when they are in the public's interest.^{83, 84} In *Whalen v. Roe*, the Supreme Court limited informational privacy rights by upholding a New York State statute that allowed the state health department to maintain a centralized database with personally identifiable information of persons who had received a controlled substances prescription. And, in another case, *Planned Parenthood of Central Missouri v. Danforth*, the Court upheld a state law requiring reporting of data to the State on late-term abortions.⁸⁵

However, in contrast, in *Whalen v. Roe*, the Court also acknowledged the bounds of government actions involving public health information. The Court held that a state public health statute may still violate a right to privacy if an “unbounded and large number of government employees” have access to the information, even if it adequately protects against public disclosure of a patient's private information.⁸⁶ And, in a 2004 case the 9th Circuit Court of Appeals decided that Arizona's abortion law violated patients' information privacy rights by requiring the “unnecessary” release of identifiable patient records to the public.⁸⁷ In other words, the mandatory reporting or collection of disease does not violate Constitutional

privacy rights but only so long as the collected information is subject to safeguards that protect the information from unnecessary disclosures to the public or too great a number of government employees. The United States Supreme Court has not fully detailed what safeguards would be adequate or what might comprise the full litmus test for necessity of disclosure. It is therefore not clear what Constitutional standards might be used to determine when the collection, use, and disclosure of identifiable or potentially identifiable health information by public health departments are appropriate.

In addition to the Constitutional provisions, there are also other federal laws and policies that comprise the legal landscape for the sharing and protection of public health information. These include the Freedom of Information Act (FOIA),⁸⁸ the Privacy Act of 1974,⁸⁹ the HHS Human Subject Protection Regulations,⁹⁰ the E-Government Act of 2002,⁹¹ the Family Educational Rights and Privacy Act (FERPA),⁹² the CDC-ATSDR Policy on the Release of Data,⁹³ the Federal Drug and Alcohol Confidentiality provisions,⁹⁴ and the Health Insurance Portability and Accountability Act of 1996 (HIPAA). FOIA guarantees public access to federal agency records or information, with some exceptions for certain types of information, upon written request.⁸⁸ The Privacy Act of 1974 protects the privacy of certain individually identifiable information maintained in federal systems.⁸⁹ A statutory provision known as the “Common Rule” provides the authority for the HHS Human Subject Protection Regulations and protects human subjects research data.⁹⁰ Although less applicable to most types of public health data and information, the E- Government Act sets out confidentiality protections that apply to all individually identifiable statistical data held by certain federal agencies.⁹¹ FERPA is a federal law that limits the disclosure of student educational records, including the health-related information, contained in those records.⁹² Federal statutes and

regulations strictly prohibit the disclosure of medical records related to federally-funded drug and alcohol treatment, which includes virtually all substance abuse and mental health treatment programs, for almost all reasons except payment.⁹⁴ The CDC-ATSDR Policy on Release of Data covers the release of CDC surveillance data sets for public health purposes.⁹⁵

The HIPAA Privacy Rule is perhaps the most often cited federal law in discussions about the privacy of health information. The Rule establishes a comprehensive, national minimum standard for restricting the use and disclosure of certain individually-identifiable health-related data or information, or “protected health information (PHI).” Entities required to comply with the rule, known as “covered entities,” include all health care providers, insurers, some government programs, and their business associates that conduct electronic transactions. Notably, however, public health authorities are not covered entities. The Rule establishes a presumption of non-disclosure and requires covered entities to engage in a number of practices to protect PHI, including establishing systematic safeguards to protect PHI, and accounting for each disclosure of PHI. Disclosures of PHI are allowed without individual authorization in the following instances: treatment by health care providers, to avert a threat to health or safety, to public health authorities for public health purposes, to protect national security, to law enforcement under certain conditions, and for judicial or administrative proceedings.⁹⁶ Although public health authorities are not covered entities and may readily receive data from covered entities under disclosure exceptions, HIPAA is an important piece of the legal landscape for the sharing of public health information because much of the data collected by public health authorities for biosurveillance purposes is obtained from covered entities.⁹⁷ And the disclosure accounting requirement of HIPAA has

been cited, although inaccurately, by health care providers and hospitals as one rationale for reluctance to participate in federal surveillance programs.⁹⁸

Under the Constitution, the federal government also may regulate the public's health through specific powers, such as the power to regulate interstate commerce and the power to direct how federal funds, including those given to states under grants and cooperative agreements, may be spent.⁴⁴ However, federal law does not complete the picture; state laws are also an important part of the legal landscape for the sharing of public health information for bioterrorism preparedness and other purposes.⁹⁹ Under HIPAA, more stringent state privacy and confidentiality laws, including those that provide special protections for specific diseases (i.e. HIV/AIDS-related information) are not preempted. And, more broadly, all powers not specifically delegated to the federal government in the Constitution, including the police power, are reserved to the states,^{11, 100} meaning state privacy laws remain an important consideration.⁵

Legal scholars have reported that most states do not have comprehensive laws protecting the privacy of health information. Instead, these scholars consider state laws to be “antiquated” because the laws describe the collection and regulation of information based on specific data recipients or particular data sources.^{101, 102} Anecdotal analysis indicate that state laws also treat some kinds of public health information as especially confidential, an approach known as “exceptionalism,” and allow broad sharing of other types of public health information. Legal scholars and privacy advocates have argued that state laws do not effectively balance competing individual interests in privacy with the need to share public health data and information for the common good.¹⁰³ Both public health advocates and privacy advocates have called for clearer privacy protections for state public health

information and suggested that HIPAA may offer a precedent for requiring privacy protections in public health information systems.^{52, 66}

Initiatives to Address State Public Health Privacy Issues

Many attempts have been made to acknowledge and address this purported imbalance at the state level between privacy interests and the need to share public health data and information. In 1988, the Institute of Medicine recognized the importance of the role of law in assuring the public's health by calling for states to review their public health codes.¹⁰ In the late 1990s, the Model State Public Health Privacy Act was drafted by scholars at Georgetown and Johns Hopkins University to address the fact that as increasing amounts of identifiable public health data are gathered, stored, and exchanged, if privacy is not maintained, individuals may suffer embarrassment, stigma, and discrimination.¹⁰² In 2000, funded by the Kellogg Foundation and the Robert Wood Johnson Foundation, the Turning Point Public Health Statute Modernization Collaborative, a collaborative of five states and several national organizations, developed the Model State Public Health Act as a tool for state, local, and tribal governments to use to modernize their public health codes.¹⁰⁴ Then, in the wake of the events in the fall of 2001, CDC funded the development of the Model State Emergency Health Powers Act (MSEHPA), which built upon Turning Point's Model State Public Health Act, to provide states with a guide for updating their public health laws relative to bioterrorism and emergency preparedness.^{105, 106, 107}

The MSEHPA, however, was somewhat controversial. It was a part of a broader CDC-initiated approach to law and bioterrorism referred to as "public health legal preparedness." Public health legal preparedness is, in part, the widely acknowledged idea that

an essential component of preparing for bioterrorism events, infectious disease outbreaks, and public health emergencies is the development of legal authorities that allow public health officials to coordinate across jurisdictions, agencies, and sectors.^{108, 109, 110} While intended to serve as a benchmark for states lawmakers to assess their public health laws with regard to terrorism and emergency preparedness, state officials were reportedly strongly encouraged to enact part of the CDC's MSEHPA to demonstrate that their bioterrorism response plans were sufficient to qualify for federal bioterrorism preparedness cooperative agreement funds.^{52, 111} Although the drafters of the MSEHPA likely intended it to balance public health powers and the need to share information with individual liberty interests, critics argue that the section that addresses the sharing of public health information, Section 303, was overly broad and did not go far enough in protecting privacy.¹⁰⁶ A 2005 article finds that thirty-three states passed some form of new law that included some or part of the language from the Model, but that many did not include language from Article 3 of the MESHPA and others adopted only small parts of the Act.⁵² Another report written by the authors of the MSEHPA states that “as of July 31, 2006, 38 states had passed statutes that reflect the principles enunciated in MSEHPA.”¹⁰⁷ I could find no information in the public domain about what specific provisions within the MSEHPA have been adopted by any particular state.

The results of the Model law efforts have never been independently evaluated and its impact on state law, in particular, has not been fully described. Experts in the field have argued that although important progress in legal preparedness has been made, no state is fully legally prepared to respond to a major public health threat. They have also suggested that the ability to detect and report a disease outbreak is not uniformly strong across the states.¹¹² The United States has even indicated that federalism may affect its compliance with surveillance

and reporting requirements of the International Health Regulations.^{113,114} Legal experts have called for state legislatures to “revisit already enacted laws to incorporate comprehensive privacy safeguards for the collection, use, and storage of information collected by public health departments.”⁵²

Rationale for this Study

The extent to which states have achieved an overall balance in their public health laws between liberty interests and the need to share information or the extent to which state laws related to the privacy of public health information enable public health leaders the flexibility they need to carry out their functions has not been documented. This study describes how well state laws achieve that balance, by: 1) examining the status of state laws and policies (as of January 1, 2009) to describe their content related to the sharing of information about potential disease outbreaks and other public health events within each state’s public health system, between law enforcement and public health within each state, and between each state and the federal government; and 2) assessing the understanding and perspectives of federal and state officials engaged in the implementation efforts around HSPD-21 and PAHPA of state public health information sharing and privacy laws.

STUDY DESIGN AND METHODOLOGY

Quantitative methods can be very useful for measuring a phenomenon.¹¹⁵ Qualitative methods, however, are most appropriate for exploring an issue that cannot be measured using scales or quantities. Qualitative methods allow for the identification of themes that emerge from narrative data. The purpose of this study is to better understand the following:

- What is currently in state public health privacy laws?
- To what extent do current laws reflect key provisions found in the Model Acts?
- Do state privacy laws meet the needs of public health practitioners today?
- Are privacy laws likely to meet the needs of public health practitioners in the future?
- Are privacy laws barriers or facilitators in achieving public health surveillance, preparedness, and response information exchange objectives?
- Is federalism understood as compatible with those same objectives?
- Is the way in which public health leaders understand privacy law aligned with existing laws?

Almost all of the research that has been done on the subject of this study, which has been limited, has been qualitative in nature. This is probably because laws, and our understanding of them, are social constructs and quantitative measurement of those constructs often has little meaning.

Two qualitative methods were concurrently applied in this study. I used policy analysis methods to capture a “point-in-time” snapshot of relevant state public health informational privacy laws in effect as of June 1, 2008. To do this, I collected policies from an online database (Westlaw) containing primary legal authorities for the 50 states and the federal government¹¹⁶ and the public health-related provisions in those statutes were compared with the recommended provisions found in the Model State Health Privacy Act (MSHPA). In addition, I conducted a total of 14 key informant interviews with federal and state public health leaders, including state health officials, attorneys, privacy officials, and federal officials engaged in the issue of public health information exchange. Descriptions of each method are presented below.

Conceptual Approach

This study, which was designed to generate a descriptive theory of public health informational privacy law, is a policy study. Such studies describe policies, explain their existence, and evaluate them¹¹⁷ by drawing on multiple approaches, techniques, frameworks, and theories, including policy analysis, evaluation techniques. Policy evaluation, a type of policy study, has emerged in the past decade as a means to assess factors in the broader social environment that affect group or individual behavior. Policy evaluation studies measure the status of state laws and have been used primarily by the federal government and by national organizations to assess the need for, and evaluate, nation-wide programs intended to achieve public health goals through policy change such as the reduction of tobacco use or the increase of physical activity.²⁴ For example, the National Institutes of Health (NIH) has used measures of state policy as a variable in a broader evaluation of the American Stop

Smoking Intervention Study,¹¹⁸ CDC has evaluated state policies as part of the State Tobacco Activities Tracking and Evaluation System to measure state progress toward tobacco control objectives,¹¹⁹ and the Robert Wood Johnson Foundation has funded policy evaluation activities as a component of its “Bridging the Gap: Research Informing Practice and Policy for Healthy Youth Behavior” project.¹²⁰ Policy studies can be formative in nature or can serve as the basis for impact analysis or studies of the correlation between policies and particular outcomes.

Study Design

In this study, two concurrent qualitative methods were used. The first method, policy evaluation, was conducted in order to determine the status of current state laws. The second method, key informant interviews, was intended to complement those findings and develop a richer understanding of public health informational privacy law.

Method 1: Statutory Analysis

Purpose. In order to assess the nature and extent of existing state privacy laws, I attempted to systematically identify, and analyze relevant state statutes, as well as case law and regulations where applicable. Because laws are essentially narratives, attempting to quantify them is very difficult and is of limited application.

Data Collection. This study collected state statutes in effect as of January 1, 2009, using an online, electronic system containing primary legal authorities for the 50 states (Westlaw).¹¹⁶ I opted to collect the statutes rather than conduct a survey or identify state laws by other means because other studies have demonstrated that legal research, performed in

conjunction with secondary research methods, such as surveys or interviews, is the most accurate means to ascertain the status of public policies.¹²¹ The laws captured in this study were human health-related only. Although animal and environmental health information is important to public health and may be considered public health information in some contexts, privacy considerations in those domains are limited. Within the laws related to human health, the types of provisions to be captured included laws related to the use of public health investigations and surveillance information; open records and freedom of information act-type laws; laws specifically related to the privacy, confidentiality, disclosure or release of human health data; and laws related to disease reporting.

Standard legal research methods used and tested in other public health policy studies were applied in this study.^{120, 122, 123,124} To identify and collect the provisions, the current, official, un-annotated versions of all state's statutes and constitution were searched using a sequence of three searches. Initially, the annotated state statutes, which contain notes about how the courts have interpreted the statutes, were used for the searches. After those searches yielded an excessive number of results, largely because it appeared that some of the terms commonly appeared in court decisions related to the introduction of evidence in criminal matters, the searches were conducted again using the un-annotated versions. In the final analysis of the statutes, the annotated versions were consulted to identify any applicable case law or regulations. In the first search, the text of the annotated statutes was searched using a series of Boolean search strings. In the second search, a scan of the table of contents was conducted, focusing on the titles within each state's code containing the health, criminal and state government statutes. These titles were reviewed for terms in the titles of either chapters or sections within the code that are similar to those used in the Boolean search strings. In the

third search, a natural language search using the phrase “disclosure of public health information” was conducted.

To confirm the findings, the list of statutes was compared against secondary data sources, such as the 50 state surveys on some topics that are provided by the online legal research database provider, the National Conference of State Legislatures websites, and reports of laws found in the literature. Although there were secondary sources that cover various aspects of this analysis in part or in whole, no existing source exists covering the entirety of the subject of this study. And, although they can be helpful in identifying any gaps or missed categories of laws, secondary sources of legal information are not always accurate or complete.¹²¹ The secondary sources and the primary research conducted for this study contained similar results. As such, secondary sources were helpful in confirming that I had not overlooked statutes that should have been included in my analysis.

Coding and Analysis. Drawing from the Model State Health Privacy Act (MSHPA) and the Model Emergency State Health Powers Act (MESHPA) and from ideas reflected in the literature about the nature of public health privacy, I developed a preliminary list of content to be captured through the analysis before the study was initiated (Table 1: List of Privacy Protections and Information Sharing Provisions) that, after reviewing the statutes from a subset of states, I narrowed to 12 total categories for coding purposes. Of the total categories or types of provisions I identified for inclusion in the final analysis, 7 were drawn from the literature: general presumption of privacy or non-disclosure (PRESNONDIS); exceptions to non-disclosure for research or statistical analysis (EXRESEARCH), contract tracing or partner notification purposes (EXCONTRACE), or to protect public health

(EXPROPH); and exceptional or special treatment for HIV (ISMHIV), STDS (ISMSTD), or other specific disease information (ISMOTH).

I used the Model Acts as a source for my decision-making about what to analyze because they represent the only sources of statutory language related to public health privacy and public health emergencies that I could identify and that has been recommended by public health and legal experts. However, after examination, I concluded neither Model Act provided an ideal set of provisions against which to compare state laws. On the one hand, the Model Acts were incomplete and arguably outdated. On the other hand, the Model Acts are highly, and perhaps overly, detailed. Both Acts contained a variety of provisions not specific to the subject of inquiry for this study.

Therefore, I focused my analysis only on the provisions in MSHPA that address the duties and obligations of health departments, the acquisition of public health information, and fair information practices as they relate to health departments. The MSHPA proposes model language on the duties and obligations of health departments that include: a duty to hold information secure; provisions that restrict the use of information to those consistent with original legitimate public health purposes; requirements to de-identify protected health information; authorizing language for the establishment of public health information officer or a privacy officer; and provisions about when public reports containing health information can be released. The MSHPA also suggests model language indicating that certain types of personally identifiable health information are not for public disclosure, require informed consent prior to certain types of disclosure, allow for disclosure of information to the federal government and law enforcement, address the availability of information about deceased individuals, and restrict secondary disclosures. To complete my final analysis, I developed

three variables or categories to measure the presence or absence of these types of provisions in state laws: public disclosure of records (MSHPAPUB), permissible disclosure to federal authorities (MSHPAFED), secondary disclosure (MSHPASECOND).

The MESHPA, which focuses on public health emergencies, recommends model statutory language for states to ensure health officials have the authority to declare and control a public health emergency, including provisions around disease reporting for the detection of an emergency and sharing of information during a declared public health emergency. I looked at the extent to which state laws reflected the provisions in Section 303 of the MSEHPA. Part C of Section 303 addresses the exchange of information between law enforcement and public health authorities. It provides that public health authorities should report cases of disease possibly caused by bioterrorism to public safety authorities and that the sharing of information between public health and public safety authorities is restricted to the information necessary for the treatment, control, investigation, and prevention of a public health emergency. I developed two categories or variables to measure the presence or absence of these types of provisions in state laws: reporting or disclosure of suspect cases of disease related to bioterrorism to law enforcement (MESH PABTLE), and explicit limitations on disclosure to law enforcement (MESH PALIMLE).

After completing the searches for the provisions, each statute was recorded. A table was created to capture the substance of each state's provisions across all the relevant sections. To analyze each statute, the text was read for its plain meaning, enacted and effective dates, legislative and administrative history, and, where applicable, annotations. Where annotations referred to a relevant administrative language or case, those documents were retrieved and coded, and the implications of those documents captured and recorded in

Table 1. Preliminary List of Privacy Protections and Information Sharing Provisions

Duties and Obligations of Health Departments

- Duty to hold information secure
- Uses consistent with original legitimate public health purposes
- De-identifying protected health information
- Establishment of public health information officer
- Issuance of public reports

Acquisition and Use of Public Health Information

- Definition of protected health information
- Acquisition of protected health information
- Broad requirement for reporting of known or suspect public health events
- Acquisition through syndromic surveillance systems
- State/local exchange of information about reported events

Access to and Disclosure of Protected Health Information

- Non-public information
- Scope of disclosures
- Requirement for informed consent
- Permissible disclosures without informed consent
- Disclosure to the federal government
- Disclosure to law enforcement
- Permissible disclosures for criminal or civil judicial proceedings
- Effect of emergency declaration on privacy practices
- Deceased individuals
- Secondary disclosures
- Record-keeping of disclosures
- Exceptions for certain disease information (e.g., HIV, genetic information, etc.)

Fair Information Practices

- Individual access to protected health information
- Limitations concerning individual access to protected health information
- Accuracy of information
- Right to appeal violations of fair information practices

Criminal Sanctions and Civil Remedies for Violations of State Law

- Criminal penalties
- Civil enforcement
- Civil remedies
- Immunities

the notes field of the table. Where sections of statutes conflicted, rules of statutory (or regulatory) construction and legislative interpretation were applied. The relevant sections were grouped by themes that emerged through the course of reading the statutes and compared with one another.

Quality Assurance. Time and budget constraints did not permit double searching or double coding of the statutes by a second person with experience in statutory analysis, the gold standard in these types of analyses. To some extent, the statutory analysis conducted for this study might be considered an art rather than a science because it is based on an approach to statutory analysis that is taught in law schools. There are likely aspects of reading and analyzing statute that, short of providing explicit detail about rules for statutory interpretation could only be easily repeated by another researcher with a legal background.

The findings from the statutory analysis were reviewed and additional analysis conducted based on findings from the key informant interviews and compared with secondary sources or lists of state privacy laws available in the literature. It is possible this method of analysis could have resulted in missed statutes. The method was intended to provide a snapshot of the general status of state laws that would allow for the identification of themes and common approaches in state laws, not a catalog of all state policies.

Method 2: Key Informant Interviews

Purpose. Key informant interviews were conducted with federal and state public health leaders for several reasons. First, and most importantly, the interviews were conducted to find out what these public health leaders thought about state public health privacy or the implementation of current federal priorities found in policies like HSPD-21 and PAHPA that

might, depending on how they are implemented, impact public health informational privacy. Second, the interviews were conducted in order to determine whether relevant state laws has been captured through the statutory analysis and whether there were any practical issues associated with enforcement or application of those laws and policies that could not be determined through the statutory analysis.

Key Informant Selection and Recruitment. Key informants were selected to represent both federal and state public health leadership perspectives. Initially, I proposed a very specific and structured approach to identifying and recruiting key informants, suspecting that I might face considerable challenges in identifying enough people willing to discuss such a sensitive topic. State and federal officials are public servants and, depending on the administration under which they are serving, can face serious repercussions for statements they make in the course of their public or private lives. As a result, federal and state officials can be very reluctant to discuss their opinions. In the course of this study, my concerns about willingness to participate was generally unfounded.

For the interviews with federal officials, participants were recruited from various federal interagency, national, and agency-specific working groups and projects addressing the exchange of human health information. The potential interviewees were contacted via email using a form recruitment email explaining the study, the confidentiality, and the nature of the interview requested. Those emails, if they received a response, resulted in a series of either emails or telephone calls to answer further questions about the nature of the study and schedule the interview. I conducted a total of five interviews with federal officials at two different federal departments who are or were involved in the effort to promote the near real-time exchange of public health information.¹²⁵ Participants at the federal level were quite

willing to participate; five of the first six people I approached agreed to be interviewed. This high rate of agreement may have been due to their professional investment in the subject matter. The interviewees included two medical doctors, two epidemiologists, and one policy official. Three interviewees worked in the headquarters of their Department and two worked at the agency level.

Recruitment of state public health officials was more complex. Initially, for this study state-level key informants were to be recruited using a directory of senior state public health officials maintained by the State Health Leadership Initiative.¹²⁶ Initially, I planned to conduct a total of 9 interviews at the state level, with one interview at each of the three states with the least comprehensive state policies, in each of the three states ranked the most comprehensive, and in three middle states. If the state health official for one of the targeted states was unavailable to be interviewed, the next state in the ranking list was to be contacted.

I encountered two challenges in attempting to carry out this approach. First, the state statutory analysis did not identify states that had clearly more or less comprehensive laws. Instead, the statutory analysis yielded patterns of differences and similarities in privacy laws that resulted in groups of states but not an easy method of ranking the states, thus making it difficult to select states using the initially envisioned method. Second, emailed recruitment letters (Appendix A) sent to the principal state health official for 15 states yielded a limited response; only 3 of the 15 states). There are several possible explanations for the low response rate to the initial mailing. State health officials in the states might simply have been unwilling to participate in an interview with a student or an attorney. They may also have been too busy to participate, given that the study took place during what is the regular legislative session for each state. Or they may have been unable to participate during what

was a time when states were facing a severe fiscal crisis, which in some cases resulted in furlough of key state employees that might have otherwise participated in an interview. Another explanation for the relatively low response rate is that the state officials may have felt uncomfortable discussing the topic of privacy law or preparedness.

When the recruitment was expanded to a second group of states selected for their geographic diversity as well as diversity of legal approaches to the issue of public health privacy, and the invitations were extended to state privacy officials and state health department legal or legislative counsel, as well as state health officers, 5 more state officials readily agreed to participate for a total of 8 states. Of the interviewees, two were in positions of scientific authority in their state public health agencies, four were in legal or policy positions, and two maintained dual roles. They were from states that were geographically, demographically, legally, and politically diverse. One mid-Atlantic state (Maryland), one southeastern state (North Carolina), one iron-belt state (Ohio), two mid-western states (Arkansas and North Dakota), one southwestern state (New Mexico), and two states in the western United States (Oregon and Washington) were represented in the interviews. According to data from the exit polls conducted by a national news organization during the 2004 and 2008 Presidential elections, three interviewees were located in states that were carried twice by the Democratic candidate, three were in states carried once by the Democratic candidate and once by the Republican candidate, and two were in states were carried twice by the Republican candidate.¹²⁷

A senior leader on public health surveillance issues for a national professional association of public health officials also participated, for a total of 14 interviews. Of the 14, at least 8 possessed doctoral degrees (Table 2. Key Informant Interviewees by Profession).

On average, the interviewees possessed approximately 15 years of public health experience. All of the interviewees had an active role in either the collection of public health data or decision-making about the use of information in a response to a public health event.

Table 2. Key Informant Interviewees by Profession

Profession	Number of Interviewees
Attorneys/Privacy Officers	7
Epidemiologists/ Medical Doctors	4
Senior Public Health Management Officials	3

Data Collection. A semi-structured telephone interview lasting based on a discussion guide and prompts were used to collect responses from key informants. The interviews were scheduled in advance to take place at a time and place convenient to the interviewee.

Extensive handwritten notes were taken during the call and the interviews were electronically recorded with permission from the participants.

One set of questions about the sharing of data and information was initially planned for both federal and state officials but after conducting one interview it became clear that the interview responses given by state and federal officials would diverge so greatly that prompts specific to each of group were needed in the discussion guide, effectively resulting in two discussion guides (Appendices B and C). Both sets of interviews focused on what laws and policies, if any, impact the ability of officials to receive or disclose public health data and information to public health officials in other jurisdictions. For the interviews with federal officials, prompts were used about the direction of federal policy initiatives to promote the real time sharing of public health information. For state officials, specific prompts and questions about their state’s laws, such as what factors they saw as influencing the

development of law and questions about future opportunities to improve the state's laws were asked. A hybrid of the prompts from both discussion guides was used to interview the individual from the national public health professional association.

During the interviews, questions were added or deleted to reflect the information the participants had already provided and to keep the interview to the scheduled time. The interviews varied between 30 and 60 minutes depending on how much time the interviewee had available and how long it took to move through the questions. As individuals agreed to the interviews and the interviews were underway, it became clear that some were eager to discuss a variety of issues related to privacy and federal preparedness policy beyond what I initially expected. Although I felt that due to IRB approval I could not dramatically alter or evolve the line of questions during the interview to utilize a true grounded theory approach,¹¹⁵ I did not discourage responses that delved into other related topics because those responses might be meaningful to understanding how the participants thought about and related to the issue of privacy and privacy law.

Protection of Human Subjects. This study was approved by the UNC Institutional Review Board (IRB). Because of the sensitive nature of the topic and the potential repercussions for some participants, protection of the confidentiality of responses in the key informant interviews was extremely important. I contacted potential key informants initially via email, a method which was as confidential as possible, although some key informants opted to include their administrative assistant in scheduling the interview. Informed consent was obtained from all interview subjects by reading a consent statement over the telephone at the start of the interview (Appendix D). The detailed written notes of the interview that were taken did not include the interviewee's name or other identifying information.

All interviewees also gave permission to digitally record the interview. Those recordings were transcribed by a professional transcription services firm approved by the UNC IRB that offered a secured system for uploading the recordings and a promise of confidentiality. After the recordings were transcribed, they were deleted from the recording device, and identifying or potentially identifying information was redacted from the printed transcripts. To the extent possible, the interview recordings and electronic transcripts were saved using non-person specific identifiers. All of the materials for the study were kept in a locked office and on a password protected computer.

Data Coding, Analysis, and Quality Assurance. Interview data was analyzed using a method known as “content analysis.”¹²⁸ Initially, I planned to use a qualitative software analysis program to assist the analysis process.¹²⁹ After attempting to use the software, it became clear that a handwritten approach would yield the same results, possibly with less effort. Key themes and ideas about public health privacy as well as the privacy of public health information in the context of ongoing preparedness efforts were identified using a node-and-tree type of approach. For example, interviews where the participant favored their state law were categorized separately from those where the participant strongly favored changes and interviews where the participant valued the power of public health to disclose information over the need to preserve privacy were coded differently. It is notable that the interviews conducted for this study were conducted with individuals with highly specialized education and experience who used acronyms, expressions, and references that might not be as familiar to other researchers as they were to me. Time and budget constraints did not permit double coding of interview notes. However, some familiarity with the terms used by the participants likely made reading and coding the interview data less complex.

Timeline

This study was proposed in the fall of 2008 and was conducted between November 2008 and July 2009. The identification, collection, and analysis of the policies took place between January and March. Key informants were selected and interviewed in January and February, and interview data was analyzed in March. Additional policies were collected and analyzed as findings from the key informant interviews necessitated. Study findings were drafted in March and July and this dissertation was defended in the summer of 2009.

Limitations of this Study

Any research study is subject to questions about validity, generalizability, and reliability.¹³⁰ Validity is the expression of the degree to which the study measured what it was supposed to measure. Because there are no statistical tests that can be used in qualitative studies such as this one, triangulation is often used to ensure validity. I attempted to triangulate my findings using two sources of data and two methods to understand and develop an understanding of state public health privacy law. Generalizability is a measure of whether the study findings can be extended to other groups or entities not represented in the study. The relatively small number of key informant interviews conducted for this study leaves open the possibility that the findings do not reflect the perceptions of all public health leaders. On the other hand, an attempt was made to capture a range of opinions. Reliability measures whether the study could be repeated. Inter-observer reliability could not be measured for this study by double-coding the interview transcripts or state statutes.

By design, the scope of this study was also limited. My research was limited primarily for explicit provisions in state laws or the annotated cases or regulations. I did not research the extension of case law or the common law to my area of inquiry. This may mean that I missed applicable cases or regulations that did not appear in the annotations of the statutes I reviewed. It may also mean that there are applicable cases, causes of action, or regulations that were missed because they did not contain the terms that I used to search for code sections. Furthermore, although a commercial database was used to collect the state laws, because the coding of the state law analysis was conducted by only one person, it is possible that applicable statutes or annotations were overlooked. The generalizability and validity of this study are discussed more specifically in the chapter containing the findings.

This study was limited to laws related to the sharing of human health information arising from public health surveillance or investigations were studied. There are a range of other legal and policy considerations in biosurveillance not covered by this analysis that include laws related to animal and environmental health surveillance, takings by the government without just compensation,⁸³ the search and seizure of property,¹³¹ and ownership of intellectual property and data. Privacy laws that relate to the other type of privacy—bodily integrity and physical autonomy—were not included in this study. In addition, statutory analysis alone, even with the limited analysis of court opinions and regulations as proposed in this study, provides only information about the laws as written; it does not take into account enforcement or interpretation. Thus, this study examined only at one part of the broader public health problem of how, when, with whom, and for what purpose public health information should be shared to detect or respond to a public health

emergency. And, it is worth noting that, while important, law is only one aspect of to any particular public health problem.¹³²

RESULTS

This chapter describes the findings from: 1) the point-in-time policy analysis of state public health privacy laws; and, 2) key informant interviews with federal officials, national organizations, and state health officials and privacy officers.

Comparative State Policy Analysis

I analyzed the public health informational privacy policies, including laws, regulations, and case law, of each of the 50 states and the District of Columbia (n= 51) in effect as of January 1, 2009 for the 12 provisions described in the Methods Chapter and recorded them in a table (Table 1, Table 2, and Appendix E). Because no measurement model exists for rating the respective value of the relevant privacy provisions in state laws, I did not try to assign values to the content of the laws as one might do where the evidence and policy base is better developed, as it is, for example, in tobacco control. Instead, I looked for the presence or absence of laws and, where laws were present, I looked at whether themes in the text of the law aligned with the Model Acts and recommendations found in the public health law literature.

The analysis revealed that after personally identifiable health information, generally or related to communicable disease status, is reported to or collected by a state health department, in approximately half of the states (25 of 51), there is no statutory provision or clearly applicable case law that imparts a continuing expectation or presumption of privacy or confidentiality of

that information.^{*} † Such information may be used and disclosed by state health officials in ways that, although it may be bounded by ethical expectations or practices, is subject to few legal restrictions. In two of these 25 states (Michigan and Rhode Island), I was able to find no statutory provisions at all that addressed the ability of public health officials to disclose or disseminate public health information.

However, of the remaining 23 states with no statutes that impart a general expectation of the privacy or confidentiality of information maintained by the health department, I found special treatment in the law for certain types of disease information related to HIV, STDS or other specific health conditions. Of these 23 states providing such special treatment, called exceptionalism, 17 had provisions related to the special protection that was required to be provided to HIV-related information, 11 had restrictions on the disclosure of sexually transmitted disease or infection (STD) information (still called venereal disease in some state statutes) and 2 had provisions related to other disease-specific information, such as tuberculosis.

Exceptionalism is controversial in public health law; advocacy organizations often find it easier to pursue bills that address their specific objectives while state officials and attorneys representing public health departments often argue such topical approaches are not supported by science or good policy. I found many ready examples of exceptionalism in my analysis. In Kentucky, the law prohibits the disclosure of an HIV test result by any person without the patient's consent except unless necessary to treatment.¹³³ In Connecticut, a law related to tuberculosis states that—

* For the purposes of this analysis, I have assumed that information reported is not the result of treatment by a health department and that health departments are not covered entities under HIPAA.

† If a statute referred to communicable diseases generally, I counted this as a broad presumption of confidentiality but if the statute referred only to HIV, STDs, or another specific disease or form of disease, I captured those provisions as narrower exceptions.

*The Commission of Public Health and the director of health for each town, city or borough shall keep a record of all such [tuberculosis] reports received by them, but such records shall not be open to inspection by any other person other than the health authorities of the state and of such town, city, or borough, and the identity of the person to whom any such report relates shall not be divulged by such health authorities except as may be necessary to carry into effect this section, section 19a-263, and section 19a-264.*¹³⁴

Connecticut also treats HIV and mental health information as somehow different from other information reported to the health authorities. In South Dakota, the law requires that “The identity of any individual appurtenant to an investigation conducted pursuant to a report of a venereal disease shall be maintained in the strictest confidence within the venereal disease control system, and any information obtained from that individual may not be disclosed in any action in any court or before any tribunal, board, or agency.”¹³⁵ Similarly, in Tennessee and in New Jersey, statutes also explicitly state that disclosure of “venereal disease” case reports is limited.¹³⁶ New Jersey restricts disclosure of information related to a person known or suspected to have venereal disease “provided, however, that the person’s physician or a health authority may disclose the name, address or identity of such person when and only when the physician or health authority shall deem such disclosure necessary in order to protect the health or welfare of the person or his family or the public.”¹³⁷

Of the 26 states in which there is language that proscribes the circumstances under which public health officials may disclose personally identifiable health information, four states (Alaska, Arizona, Indiana, Oklahoma, Oregon) have provisions for each of the three exceptions I analyzed for this study—exceptions for disclosure when public health officials deem it necessary to protect the public’s health or the health of an individual, exceptions for statistical analysis and research, and exceptions for disclosure to a contact or for contact tracing purposes. Of the 26 states, an additional 10 had at least two of the three exceptions and 23 of the 26 had exceptions

for protecting the public's health. For example, in North Dakota, a report to the state health department is confidential information. The information "may not be disclosed, shared with any agency or institution, or made public, upon subpoena, search warrant, discovery proceedings, or otherwise, except that" disclosure may be made for statistical purposes if made in a manner that no individual can be identified, to enforce the reportable conditions statute and for treatment, control and investigation of HIV infection, or disclosure to medical personnel to the extent necessary to protect the health or life of any individual.¹³⁸ In Washington, disclosures are permitted to federal, state, or local public health authorities when needed to protect the public's health.¹³⁹ Arkansas has a unique statute. It allows state, county, or local health officer to disclose communicable disease information if the disclosure is: authorized or required by state or federal law; permitted by written authorization of the individual; for contact tracing purposes; for necessary for research purposes; or "for the purposes of conducting a search of the national death index."¹⁴⁰ However, the statute is silent on whether disclosure is authorized to protect public health generally, possibly because this is assumed to be a power of the health department.

Maryland, Nebraska, and New Hampshire had no apparent provision explicitly allowing the disclosure of health information when health officials deem it necessary. Interestingly, even though these 26 states have clear language related to how and when information can be disclosed by public health officials, some of the states treat certain types of disease information differently, usually by subjecting disclosures of that information to more stringent standards. Eleven of the states have specific provisions related to HIV, four have language related to special treatment of sexually transmitted disease information (also called still referred to as venereal disease by some state statutes), and 5 have provisions related to TB, genetic or other types of specific diseases.

Table 3. States with general privacy, use and disclosure, and exceptionalism provisions

State	General Provisions	Exceptions to Use or Disclosure			Exceptionalism		
	Presumption of non-disclosure	De-identified for statistical analysis	Contact tracing/ partner notification	Protect public health	HIV	STDs	Other conditions
	PRESNONDIS	EXRESEARCH	EXCONTRACE	EXPROPH	ISMHIV	ISMSTD	ISMOTH
AL	Yes			Yes			Yes
AK	Yes	Yes	Yes	Yes			
AZ	Yes	Yes	Yes	Yes	Yes		Yes
AR					Yes		
CA			Yes		Yes		
CO					Yes		Yes
CT							Yes
DE	Yes			Yes	Yes		Yes
DC	Yes	Yes		Yes			
FL					Yes	Yes	
GA						Yes	
HI	Yes			Yes	Yes		Yes
ID					Yes		
IL					Yes		
IN	Yes	Yes	Yes	Yes			
IA					Yes		
KS	Yes *			Yes			
KY					Yes	Yes	
LA					Yes		
ME	Yes			Yes	Yes		
MD	Yes	Yes					
MA						Yes	
MI							
MN	Yes	Yes		Yes			
MS					Yes		
MO					Yes		
MT	Yes	Yes		Yes	Yes	Yes	Yes
NE	Yes	Yes					
NV	Yes	Yes		Yes			
NH	Yes	Yes					
NJ	Yes			Yes		Yes	
NM	Yes	Yes		Yes	Yes	Yes	
NY					Yes		
NC	Yes			Yes			
ND	Yes			Yes	Yes		
OH	Yes	Yes		Yes	Yes		
OK	Yes	Yes	Yes	Yes			
OR	Yes	Yes	Yes	Yes			
PA	Yes			Yes	Yes		
RI							
SC						Yes	
SD	Yes	Yes		Yes	Yes	Yes	
TN					Yes	Yes	
TX	Yes	Yes		Yes			
UT	Yes		Yes	Yes	Yes		
VT					Yes	Yes	
VA					Yes		
WA					Yes	Yes	
WV					Yes	Yes	
WI						Yes	
WY						Yes	
TOT	25	16	7	23	28	15	7

* Distinguishes between infectious and non-infectious disease.

In addition to the finding that only about half of states had provisions that imparted a general expectation of non-disclosure, or privacy, of personal health information maintained by public health officials, I found several other notable aspects of state laws. Although I was not initially looking for this exception and I did not record which states had such a provision in my analysis, I noted that a few states allow disclosures with consent. I also noted that, in some states, disclosure of personally identifiable health information from one state agency to another appears to be prohibited. For example, in Connecticut, the Medicaid program may only obtain information that supports payments for the care of individuals receiving medical assistance.¹⁴¹ In other words, the Medicaid program appears to be prohibited from receiving information with the health department about particular enrollees. While this may be a necessary privacy protection, from a public health perspective, it may present a lost opportunity for collaboration between the healthcare delivery and financing system and public health authorities seeking to design or deliver interventions for at risk populations.

One state, Kansas, distinguishes between the disclosure of infectious and non-infectious diseases in its statutes in a way that other states do not.¹⁴² The statute relating to the disclosure of noninfectious disease information states:

Information concerning noninfectious diseases obtained by the secretary under K.S.A. 65-102 is confidential and shall not be disclosed except as provided in this section. The secretary may disclose information concerning noninfectious diseases obtained under K.S.A. 65-102: (a) Upon the consent, in writing, of the person who is the subject of the information, or if such person is under 18 years of age, by such person's parent or guardian; or (b) upon the request of an organization or scholarly investigator for legitimate research or data collection purposes so long as such information is disclosed in a manner which will not reveal the identity of the persons who are the subject of the information.

Montana was the only state with language that specifically allows for the release of information to another state—

Table 4. States with selected MSHPA and MESHPA provisions

State	MSHPA			MESHPA	
	Public record	Permits disclosure to federal authorities	Secondary disclosure	Suspect BT cases disclosed to law enforcement	Other disclosure to law enforcement
	MSHPAPUB	MSHPAFED	MSHPASECOND	MESHAPTLE	MESHPALIMLE
AL					
AK					Yes
AZ		Yes	Yes		
AR	Yes				
CA	Yes				
CO	Yes				
CT	Yes				
DE	Yes	Yes	Yes		
DC					
FL	Yes				
GA	Yes				
HI	Yes				
ID	Yes				
IL	Yes				
IN	Yes				Yes
IA					
KS	Yes				
KY	Yes				
LA	Yes				
ME	Yes	Yes	Yes		
MD	Yes				
MA					
MI	Yes				
MN	Yes		Yes		Yes
MS	Yes				
MO					
MT	Yes	Yes	Yes	Yes	
NE	Yes	Yes			
NV					
NH	Yes				
NJ	Yes				
NM	Yes	Yes	Yes	Yes	Yes
NY	Yes				
NC	Yes	Yes			Yes
ND	Yes				
OH	Yes				
OK					
OR	Yes		Yes		
PA	Yes		Yes		
RI	Yes				
SC					
SD					
TN	Yes				
TX		Yes	Yes		
UT	Yes	Yes			
VT	Yes				
VA	Yes				
WA	Yes				
WV	Yes				
WI	Yes				
WY	Yes				
TOTAL	39	9	9	2	5

* Distinguishes between infectious and non-infectious disease.

*Health care information in the possession of the department, a local board, a local health officer, or the entity's authorized representatives may not be released except: ... to another state or local public health agency, including those in other states, whenever necessary to continue health services to the named person or to undertake public health efforts to prevent or interrupt the transmission of a communicable disease or to alleviate and prevent injury caused by the release of biological, chemical, or radiological agents capable of causing imminent disability, death, or infection.*¹⁴³

I also found that of the almost half of states (23 of 51) that had provisions expressly allowing disclosure of public health information when, in the opinion of public health officials, it was necessary to protect the public's health or the life of an individual.

Interestingly, however, none of these states' laws indicates what criteria might be used to determine when disclosure is essential to safeguard the public's health. Although the laws themselves are relatively simple, the meaning and scope of the laws is not clear. In the course of my analysis, I found no judicial opinions that might help to interpret the scope of the laws. The variety of approaches across states opens a question about whether the privacy and security of information in the possession of public health authorities varies greatly across states or state policies are not aligned with best public health practices. There is likely some commonality in the criteria used by public health practitioners in determining when the disclosure of data is essential to public health but it is not clear, at least from the policies, what criteria are used.

In total, I found that 28 states had provisions that provided special protections for HIV information, 15 had provisions for STD information, and 7 had provisions for other diseases. These exceptions for certain diseases or conditions do not mirror the recommended approach found in the Model Acts or in the legal or public health literature. Moreover these types of statutes may be contributing to confusion and disagreement among public health officials about how and when public health information should be or is disclosed. I also found that in total only about one-third of states had explicit provisions that allowed for the use of personally identifiable

or potentially identifiable health information collected by the health department so long as the data were not identifiable or potentially identifiable when released to the public (16 of 51). Less than a quarter of all states had language that addressed: disclosure to contacts of a person with a communicable disease, in some cases including pre-hospital personnel exposed to the bodily fluids or respiratory droplets of a person with particular infectious diseases (7 of 51); disclosure of public health information by the state to federal public health officials (most specifically mention CDC or the Department of Health and Human Services) (9 of 51); secondary disclosure of personally identifiable information provided by the health department to a third party (9 of 51); and, when certain types of health threats may or must be disclosed to law enforcement (6 of 51).

And, I was able to identify provisions in 39 states that reflect public records act language, sometimes referred to as sunshine or freedom of information acts. In most states where I was able to identify provisions, the statute appeared to require that all public records be made available or accessible to the public and then the statutes set out a series of exceptions, usually including health or medical information maintained by the state or in some cases, information that disclosure of which would constitute an “invasion of privacy.” But, the meaning and application of the provisions could have been clearer. In many states, confusing or inconsistent terminology likely necessitates a case-by-case analysis or reliance on the application of case law from other domains.

Overall I found that most states have remarkably few statutes, regulations, or judicial opinions of any kind that proscribe the manner in which public health agencies should maintain the privacy of disease information or when public health authorities should or may share information with other government agencies or the public. But why do so few states have

provisions that lack detail about what public health authorities can and cannot do with the personally identifiable information they collect and maintain? It is not possible to provide an answer with certainty based on this analysis. One possibility is that the common law privacy right under which a health care provider is expected to maintain the security and confidentiality of a person's health information, known as the "patient-physician privilege," is often misunderstood to apply to public health authorities as well. Common law is law that arises from the decisions of judges; most common law in the United States has its origins in the legal system of England adopted when the United States was founded. States have adopted this common law patient-physician privilege with some statutorily imposed exceptions, including the exception for disease reporting. I did find that states had extensive statutes that addressed the disclosure of information by health care providers.

Given the general expectation of privacy for information possessed by a health care provider, it is possible that there is a general misconception that these protections extend to information passed on to or collected by public health authorities. However, the common law imparts no expectation that the government or public health authorities will maintain the security and confidentiality of information obtained for public health purposes. And, this analysis suggests that statutes also offer little protection or guidance for how information should be used. In most states, although medical records are not generally required to be provided to requestors under state freedom of information act or sunshine laws, public health authorities do seem to have the power to disclose virtually any record they deem necessary.

Until the mid 20th Century, when understanding of the disease and treatment options were limited, state and local public health authorities routinely disclosed the name and addresses of individuals with infectious diseases in newspapers to warn or protect others from exposure.¹⁴⁴

This may suggest that public health authorities themselves have lobbied in states against any restrictions that would prevent their use of the information they collect, a theory corroborated by the suggestion of key informants' expressions of pride that at the federal level public health had successfully put a "hole you could drive a truck through" in the Health Insurance Portability and Accountability Act. (See next section: Key Informant Interviews). This might also explain the unusual treatment in the law of certain types of disease information, such as HIV diagnoses, discussed earlier. If public health officials are or were reluctant to have any legal parameters that either mandated disclosure or privacy protections for public health information, the exceptional treatment of certain diseases may be an expression of compromise on the part of health officials.

Also, I found it notable in my analysis that I found nothing in state laws that spoke to the impact of a public health emergency or potential emergency on informational privacy rights. While there was nothing that indicated procedures or approaches to privacy would change in the event of a public health emergency, there was also nothing that indicated that the approach to informational privacy would change. This may not be a meaningful finding. Generally, speaking, however, it seems possible that if there were a major or prolonged public health event affecting large numbers of people, such as pandemic influenza, there might be a need for disclosure of names or other personally identifiable information for the purposes of quarantine, isolation, or distribution of vaccines or anti-viral medications. It is also possible that it might be impractical for public health authorities to maintain compliance with laws that require them to keep records of individual disclosures or perform a case-by-case analysis of whether there is sufficient public health need for the disclosure of a particular case report.

It is not clear whether the absence of the recommended provisions examined for this study indicates something about the practical value of the model laws used to inform this

analysis. It may be that the model provisions, while logical, were simply not relevant in states where opportunities for policy change have occurred since they were written. After all, as Oliver Wendell Holmes once famously said, "The life of the law has not been logic; it has been experience...The law embodies the story of a nation's development through many centuries, and it cannot be dealt with as if it contained only the axioms and corollaries of a book of mathematics." One interviewee reported being the case in his state, the provision in the Model Acts were not deemed as necessary by state public health officials. A second interviewee reported that he was simply not successful in building the will to have the recommended policy provisions implemented in his state. Although not reported by interviewees, it is also possible that public health officials are not educated about the need for policies written in the Models and did not pursue their implementation.

Key Informant Interviews

The results from the key informant interviews include verbatim remarks as well as interpretation and classification of remarks. There is no index of the interviewees to further protect their anonymity (i.e., use of a cross-listing of remarks by certain interviewees).

State Public Health Key Informants. State health officers, legal counsel to state health departments, and state health privacy officers served as the second group of key informants in this study. Unlike federal officials who framed their discussions of privacy in terms of trust and information sharing, state officials indicated that the protection of privacy was a critical day-to-day issue in their work. In the interviews, state officials made comments that can be loosely grouped into five major thematic areas: 1) characterizations and descriptions of state privacy and disclosure laws; 2) the practical implications of privacy law in state and local public health

practice; 3) the factors influenced the development of privacy laws in their states, including the interest groups that influenced the development and implementation of those laws; 4) the relationship between the state and federal government around privacy and the exchange of public health-related information; and 5) ideas and opportunities for policy development in public health privacy and information sharing to facilitate state public health practice. Although there was a great deal of consistency in the ideas expressed by state officials, within each of these areas, the interviewees expressed multiple and sometimes conflicting themes and opinions. These findings are described in detail below.

If you have seen one state privacy law, you have seen one state privacy law

When asked to describe or characterize their state privacy laws, the state officials responded with laughter, a sigh, or some indication of the extraordinary difficulty of describing their state's approach to protecting the privacy of health information, especially public health information. State officials expressed the variety of approaches that have been taken by their states over the years that have resulted in numerous and complex statutes and regulations. State officials reported that in some cases, relevant state law can be found in mainly in statutes but can also be found in case law and regulations. They discussed it as being a difficult and "complex" area of law with "important implications" for their work.

Despite the difficulty in describing their state laws, officials' comments generally could be grouped into one of two dominant models or patterns that their laws followed. In the first model, they described a disease-by-disease set of provisions in which privacy requirements are linked to the disease and the statutes specific to that disease. In the second model, states described some sort of organizing or overarching privacy law with a series of exceptions. In the

first model, where the law is found in statutes, interviewees indicated it is rarely found in a single statute or even in the same chapter of a state's code. One interviewee described it by saying:

Well, it's really all over the place, which one of the many challenges. We have our own sort of mini state HIPAA provision, which for public health doesn't come into play that often unless we want to use it as a basis for refusing to release information. The disease reporting statutes have their own confidentiality provisions. The HIV/AIDS laws have their own confidentiality provisions. Immunization records have their own, and they are all slightly different."

In describing states that followed the second model and seemed to have more intentional approach to the privacy of public health information, one interviewee reported "We start out with the very general principle that confidentiality with respect to medical records and other items are protected under law. And then that's carved out with several exceptions to that when you can disclose medical information." Another interviewee described a similar approach in which the authority was given to health department to create exceptions to a strict protection of confidentiality or privacy via rulemaking. Still another said: "Although we didn't have a specific statutory basis for it, there is a catchall provision to protect confidentiality if there is no specific statute, and that's in case law we have in [this state]."

The decision to disclose or not disclose is an important one for state public health officials

Interestingly, interviewees seemed to use the words confidentiality, privacy, and protection of health information interchangeably to mean the following: holding secure personally identifiable information or data from being viewed by too great a number of people; ensuring that the information or data is known only to those people who will use it to carry out a public health purpose; and ensuring that the information is used as judiciously as possible to avoid unnecessary disclosure and stigmatization of the individual. State officials talked about

why protecting privacy is so important in ways that were similar to federal officials, focusing on trust and relationships. “In my experience, state health agencies are acutely aware of the need to preserve and protect health information, not just because of the statutory authority, but because we need people to trust us in order for us to do our work.”

However, state officials also expressed a willingness to use or disclose information if necessary, something that was not discussed by the federal officials interviewed.

If it is a disease of condition that leads to an imminent danger to the public, and it's necessary to prevent a serious or imminent threat to the health and safety of the public, then we do and would release that information...And we don't believe that's inconsistent with our state laws because in certain cases being able to share that information...we would not only do it, but we consider it our obligation or duty to do so.

They also discussed the need to share information within the public health community. “To the extent that we cannot or do not fully share important information with each other, we’re not doing our jobs. So, to the extent that laws get in the way of that, we have to fix them.”

In discussing the release of information, state officials indicated that there are limitations on how much information can be released and how it can be released. They were very aware of the potential for misuse of data and information. “We are very aware of the potential for some misuse there, and so we go to great lengths to ensure that whoever does have access has it in a very appropriate way.” Almost all the state health officials indicated that, in their state, disclosure of information requires a case-by-case analysis. “You have to think through what you’ve got. It’s sort of a HIPAA analysis in some respects.” “People often look for the black and white answers to confidentiality questions, and it’s surprising how often there are not black and white answers in the law.”

This creates the need for health officials to do a case-by-case analysis each time that public health information may need to be disclosed. Talking about how each situation requires its

own analysis in determining if disclosure is appropriate, one interviewee described a situation in which the state had to make a difficult decision. “This woman had food [establishment], and she had a sick kid there at the food [establishment], and the food got contaminated and a bunch of people got sick. And, somebody wanted [the state health department] to disclose the name of the [food establishment]. We felt like we couldn’t do that without disclosing, actually, the person who was sick.”

To address these privacy challenges and still achieve the public health purpose, the key interviewees talked about creative strategies and approaches. One state official told a story about the early stages of recognizing an emerging infectious disease in their state. “We had the first death of West Nile. The press wanted the details, a human interest story.” Health officials in the state wanted to warn the public in the affected region of the real dangers of West Nile virus and the need to take preventive measures like covering up, wearing mosquito repellent, and eliminating man-made areas of standing water. However, after doing an analysis of what could be released about the fact that a death had occurred, the state health officer and state public health attorney decided that they could not release any of the details, such as the county, age, or sex of the person who had died because in the rural area where the death occurred, it would be relatively easy to determine the identity of the affected person from the obituaries and other public records. Still, wanting to both respect the privacy of the grieving family and educate the public, the public health official asked the family if they would agree to talk to the press. The family agreed. The state health department and the family held a joint press conference that provided an opportunity to honor the person who had died and educated the press and the public about the measures to take to avoid exposure to the West Nile virus.

Still, in more complex situations, such as large outbreaks of disease or highly political situations, state health officials reported that sometimes there was no good solution. They suggested that in certain occasions, trying to avoid the request for disclosure in the first place was the best solution. They said the best way to do this is by not collecting any information that is not absolutely necessary in the first place. One state official said, “That’s probably an important take home—you can set up your systems so that you can make it easier to deal with the privacy rules by separate what’s obviously private from what isn’t, or what ultimately is going to be requested and can be released without disclosing confidential information.”

State public health privacy policy have developed “organically, not logically”

According to the state officials interviewed for this study, not all state laws that impact the ability of state health officials to disclose or maintain the privacy of health-related information are ideal or easy to work within. As such, it seemed important to explore what state officials thought about why and how state public health privacy laws came to look the way they do. The state officials who participated in this study cited one or more of four reasons why their laws look the way they do today: 1) need; 2) state-specific events; 3) federal policy developments; and 4) events in the fall of 2001.

Need was by far the most common reason cited by participants. One state official described “need” as gradual change over time where their professional judgment suggested something needed to be changed and the opportunities to make those changes present themselves. The state official said, “There are several little adjustments that happen every year to our confidentiality and privacy laws that I think are good. I think we are beginning to refine it now and just not saying that we need to balance between the confidentiality, but then we also

have to have this access for public health safety available as well.” Another state official said, “Well, we keep coming up with these sorts of problems with our...ability to protect the information, or our ability to get information, or to release information. And so over the last year and half of talking to the same folks we—I don’t know if I suggested it or they suggested it, but I think we really need to clean this up.”

State officials also cited the role of specific events where privacy was violated in a very public way as leading to major changes in their state’s laws. One state official who served as a state official described a situation in which state officials requested access to a series of records. That request lead to a series of political events which in turn resulted in the passage of a bill that now requires state officials to take very extensive steps in their daily work to protect privacy. Another state official talked about how having a state health director that was interested in public health law resulted in a total re-write of their laws. Still others described how the emergence of certain diseases or conditions in their states led to the passage of new laws.

Most state officials also talked about how their laws have been strongly influenced by federal policy developments. Citing an example of when they made significant changes to their state’s laws, one interviewee said, “Probably back in 2001, 2002 we were already dealing with privacy issues. And as HIPAA kicked in, we really entered into it in a very aggressive way.” The Health Insurance Portability and Accountability Act (HIPAA) was also cited by other interviewees as a major precursor to changes in state laws. Other examples cited included federal preparedness policy. One interviewee talked about federal requirements to do preparedness planning and indicated those new federal policies prompted them to review the state’s ability to withhold certain types of sensitive information that might be a security risk if disclosed during an event.

Several interviewees described making major changes to their laws after September 11, 2001. One interviewee described being asked by the Governor right after the anthrax attacks to come down and have a conversation about needs of the health department if some other major public health event occurred. That conversation led to significant changes in the state's laws. The interviewee talked about how the situation presented an opportunity that was extremely important to shaping his state's law. The interviewee said he told his colleagues, "It's time to give me every gripe, every concern, every issue that you have ever had with our laws...The last time [we had this chance] was 100, just slightly under 100 years ago, so now's the moment" to make the confidentiality laws consistent with practice as well as accomplish other policy goals. Describing the series of events, the interviewee said, "It was done under a very quick time crunch. Initially what it is—it was in reaction to the 9/11 attacks, and the anthrax attacks particularly because that really affected—like every else, that was really affected—and the scare, and all that sort of thing. It affected the department." A second interviewee talked about a similar situation. He described how right after September 11, 2001 his state made changes to the law that increased access to identifying information and increasing the ability to make people give up information that might be needed by the health department and other state agencies.

The result of all these forces, state officials reported, was and is a "hodgepodge" of laws. A law gets written "but they didn't bother to check the other laws that were already on the books to make sure that they harmonized." "We have piecemeal changed things...some things get updated and other things just fall by the wayside because there isn't really a constituency to push it, basically. It's a lot of work to get a bill through the legislature." One state official described their laws as growing "organically, not always logically. It's a little bit like evolution. It goes along and goes along and then all of a sudden it has a mutation somewhere and that, for whatever

reason, either works or doesn't. If it works, it gets perpetuated." The state officials were pragmatic about policy development and their contributions to the law. One said, "It sort of depends on whether or not it's anybody's priority...It's all a crapshoot."

Several state officials talked about the release of model laws, such as the Model State Emergency Health Powers Act, and the influence, or lack of influence, of those models on their decisions. "CDC and the model acts weren't the cause [of changes in my state's laws] but were helpful resources." One state official described using those models by saying, "Now what we didn't want to do was sort of take it [model act] lock, stock, and barrel. We really wanted—we didn't want to amputate the leg if all we needed to do was cut off the toe. So we really tried to take a more surgical approach to incorporating the recommendations of the model act into [the state code]."

Interest groups were described by the key state officials as important to the way in which privacy policies developed. Interestingly, state health officials seemed to be consistently, although perhaps unknowingly, describing themselves as a key interest group shaping in privacy laws.

"We're in the process of trying to revamp the confidentially provisions regarding reportable diseases...it only protects the person—the identity of the person with a reportable disease—and there are lots of times during a disease investigation outbreak where you talk to and get health information about people that may have been exposed, or controlled—things like that. We want to make sure that we can protect that information. We've also had problems with people assisting during an investigation and getting us the information that we need... We're trying to make it so that we could release information about someone with a reportable disease to someone that had been exposed to a reportable disease under certain circumstances."

They also described a number of other interest groups that have influenced their privacy laws. On the side of favoring disclosure, they indicated that the plaintiff's bar, the news media, and certain community groups have played a role in shaping policies. Explaining the interests of the

plaintiff's bar, state officials said, "Public disclosure is discovery on the cheap—as well as, simultaneously- we have the issues going on simultaneously—we also have people using public disclosure for initial discovery." For that reason, one state official indicated, plaintiff's attorneys in one state are opposing a bill to restrict access to certain types of information on death certificates.

State officials reported that the news media, including radio and newspapers, lobby for policies that encourage the disclosure of information. In describing one encounter in a policy development process, one state official said "The media interest in a cause of death is very- I was surprised at the amount of pressure." Another state official said, the news media seems to have a particular interest in any policy related to the privacy of public health information "...particularly if you try to overreach outside of solid group areas like communicable disease. Yeah, they get a lot more interested- death certificates and birth certificates kind of thing. When you extend it beyond- or try to expand it [privacy protections] beyond traditional medical information, yea, there's a lot of interest from the media- and push back." The interests of the plaintiff's bar and the news media were described as being economically motivated. Disclosure may reduce the cost and barriers to the work of their professions.

Interestingly, state officials also described a third type of pro-disclosure interest group. This group is difficult to label but state officials noted this group has a real influence over state legislators. One state official, expressing some frustration, described them this way:

We have some folks that call and want to know if there has been a person who has developed Methicillin Resistant Staph infection in their community, or someone that has died of Vancomycin Resistant Enterococcus disease. They feel that they need to know who those people are so that they can isolate them. And the individuals will call and say we have every right to know because we don't want these people in our community or we don't want to associate with them. You should put a card around their neck and say that they are MRSA so that we can avoid them.

Agreeing, another state official simply said, “There are groups that really push hard for specific disease related information. Most of the time for reasons that are not consistent with good public health practice.”

Overall, state officials seemed to indicate that the interest groups that favored limiting disclosure, such as civil liberties advocates and HIV/AIDS advocates, were not as significant a factor in the development of the laws as the groups that were in favor of disclosure. When state officials commented specifically on the influence of the American Civil Liberties Union, there was a divergence of opinion. One state official said “The ACLU will get involved from time to time but not a whole lot. We don’t have a big privacy interest out there right now.” Another interviewee said “[The ACLU is] actually less focused, I think, on health records than on other things, like police activities around political activists.” A third interviewee said “[The ACLU] were involved in our work around updating our isolation and quarantine laws, and they pay attention to this stuff.”

Similarly, there was some variation in opinions about the role of HIV/AIDS advocates as a pro-privacy interest group. One interviewee said, “The climate has changed dramatically. They [the HIV advocates] are a lot more supportive of the issue [of disclosure]—we don’t have knockdown drag-outs like we did in the past.” Another said, “HIV/AIDS primarily folks are certainly, for good reason, would not want to do anything that would open things up [for disclosure].” Still a third said, “The HIV/AIDS community is always very concerned about what kind of information is out there. We’re trying very hard to mainstream—for collection and operational purposes—HIV/AIDS...”

On the variety of other disease-specific advocacy groups, one interviewee said “Depending on which [disease] you’re talking about, it’s just par for the course that you find persons who are knowledgeable in the community, and you have your discussions before you take it to the general assembly, not afterwards, at least as much as you can.” Key informants also cited the defense bar and medical associations as having an interest in protecting privacy. “The defense bar goes out of its way to try and ensure that whatever information we have is ‘confidential’.”

State-Federal public health information exchange: A voluntary relationship

State key informants were asked to talk about their perspectives on privacy and disclosure of public health information to the federal government. They were quick to point out that all sharing of public health information between the states and the federal government is voluntary; there is no federal law requiring the reporting of disease information to CDC or any other federal agency. However, they also emphasized that they do willingly and openly cooperate with CDC by providing as much information as is “appropriate and necessary.” They said, “we need [CDC] to have the data; [CDC] need[s] it to know if there are multistate outbreaks.”

They indicated they had not had problems with CDC with reporting specific instances of unknown illnesses or in reporting Nationally Notifiable Diseases. “I’ve not seen CDC step over the bounds. In fact, it seems like they’re incredibly conservative in confidentiality issues, whether it be XDR TB, or whatever. I mean I think they have tried to handle those and are very cognizant of confidentiality issues.” Another interviewee, talking about why their state gives data so willingly to CDC said, “We look at them [CDC] in kind of the same we’re being looked at in

the state. Public health has an obligation to all the people in the nation. And, sometimes, confidential information is important to either quell or respond to an epidemic or a problem.”

Notably, however, key informants had slightly different attitudes toward sharing data with CDC via syndromic surveillance systems. They cited concerns about the usefulness of syndromic surveillance data in the hands of people without a public health background.

We were very, very reluctant because of the ambiguity, to play in the sandbox...because our concern was that some of this might end up in Homeland Security, and in places where public health data would be fundamentally misconstrued because they just didn't have the appropriate background to look at it and understand what they were looking at. For them, what looks like a monumental problem, we said, oh no, no, that's not unusual. I'm sorry, it's July, and yes, we have a huge spike of gastrointestinal complaints; it's Grandma's chicken salad. People leave food out in the sun.

Key informants also raised concerns about the control and ownership of data in national syndromic surveillance systems. “In writing the legislation for our state’s syndromic surveillance system, we had to be even more restrictive on protecting privacy than we normally would have been in order to sell it to our partners—and for good reason.” The interviewee described how that “good reason” was that the massive volumes of data available in a syndromic system posed not only a threat to individual patient privacy but also to the proprietary interests of hospitals and other healthcare providers. For example, data about how many of what kinds of procedures are done and the rate of bed occupancy are extremely valuable in a competitive health care market. Then, the interviewee went on to describe how when they finally agreed on the need to share that state’s syndromic surveillance system data with the CDC, they had to change the state law that covered their syndromic surveillance system. “One of the difficult issues of negotiating that was how—what were they going to do in sharing it with others at the federal level.” The interviewee described the challenges in brokering an agreement on data use and disclosure that met both the

needs of the health care facilities as the data providers, the needs of the state, and the needs CDC.

The key informants that participated in this study cited one critical issue in their information exchange relationship with the federal government—the presumption that information being shared is being shared for “public health purposes” only, meaning for a public health investigation, research, or to build an evidence base for public health action. For example, one interviewee said, “If your federal partner has a secondary objective that takes it outside the public health realm, re-disclosure [by CDC to another agency] could be an issue.” And, “If CDC or HHS was going to share data with Homeland Security that would concern me.” Another interviewee said, “We’ll share at the state level within the confines of our laws.”

Although interviewees expressed their willingness to share data within the public health system and for public health purposes and their appreciation for federal technical assistance and funding, they did take the opportunity to talk about what one interviewee called “role confusion issues” at the federal level. “We are a federal, state and local system. We’re going through a period now where there’s some debate, and some confusion, about whose role it is to intervene in a public health event. Typically, that’s the state’s job.” They talked about how some of this confusion seemed to be related to syndromic surveillance, citing examples where certain federal government programs gave the appearance that they wanted to intervene in state public health issues when federal syndromic surveillance systems suggested a public health event might be occurring. Another interviewee said,

The federal government was all over the place as far as where they wanted to go with preparedness. I mean Homeland Security and the Department of Health and Human Services; we’re not sure who is in charge of pandemic flu. If you listen to one they would say we are, and if you listen to the other, they’d say the other one is. And I don’t know what was happening in the previous

administration, but somebody should have sat down and said this person is in charge or that person was in charge.

Interviewees indicated that this confusion made them “wary” of some federal agencies intervening in state public health issues.

Opportunities for creative state public health policies to balance privacy and disclosure

State officials suggested that although their policies generally work for them in protecting privacy and disclosing information when there is a need to do so, there is still work to be done and unanswered questions to address. To the extent planning around those issues could help them to improve their effectiveness in protecting the public’s health; they seemed to have an interest in pursuing new approaches. For example, one state official said “I have no doubt that our statutes are not perfect I know they’re nowhere near. There are probably a lot of things we can do and should do to try to improve.” Another said, “I’ve learned to say that we’ve yet to write the perfect statute on any of this.”

State officials talked a great deal about how developments in information technology developments may be changing what is needed in state public health privacy laws. One state official said:

I am looking down the skyline here at [a major University]; there are brilliant people who will be able to do data mining, at least in theory, beyond anything we’ve conceived of. The more those records become electronic, that will become an issue. It’s one thing when the doctor sends in a particular lab report, faxes it in, but everything was online and this was instantaneous, I don’t think we’ve heard the last of privacy, nor should we, I guess.

Another said, “As we move into this electronic transmission system, there seems to be greater concern about the privacy protections. Will they survive as you move through state and federal agencies?”

Several state officials talked specifically about the role of privacy law in Health Information Exchanges (HIEs), virtual networks of health care providers that exchange electronic health records across jurisdictional lines. They asked questions such as “What rules apply to them? What laws apply to them? What remedies apply? If there’s inadvertent disclosures?” One state official said, “If there are laws that apply to health information exchanges, I haven’t seen them. So, we try and put it in a contract? We’re going to sue Iowa’s clearinghouse? I don’t think so. So all of that I think is going to develop over time.” Another state official said, “The relationship between public health records and the need to keep them private...If you’re going to enhance surveillance and disease prevention, you need to do everything you can to keep those records private. That would be one area where I’d see development. The whole electronic record area is going to have to be scrutinized.” They also discussed the need to address the challenges in understanding how emergency statutes and privacy laws interplay. One suggested that “something to look at would be basically are the existing non-emergency public health confidentiality statutes, would they continue to apply in a public health emergency?” Some state officials suggested that this question has not really been tested at the state or the federal level because a true test would require a pandemic or similar type of event.

To address these unanswered questions, the state health officials who served as key state officials in this study suggested a need for building better relationships between states on privacy and information exchange issues, the development of model laws that encourage states to consider these issues, and a privacy framework that provides a foundation across states and the federal government on which public health information can be exchanged. To build relationships among states, state officials talked about how states are establishing agreements among

themselves to meet their needs for sharing information. One state official described how a group of states has started developing these relationships on their own:

We have actually signed MOUs between...states to work together in these areas at a regional level...It's actually organized around preparedness issues. And, what it's meant to do is on a regional level to have regionally what nationally we would have as Emergency Management Assistance Compact (EMAC) on a declared emergency nationally. But we have the same for understandings in place even when it isn't a national emergency.

State officials talked about how achieving these better relationships between states or developing new model laws would require a vision for confidentiality and privacy of public health information. "I think that if anything would help us, just to know that yes, this is the way it's going to be. This is what we need to aim at. This is what we need to kind of design our programs around." They disagreed, however, on how a common understanding across states should be accomplished. One state official said, "I think we need to have a federal, a fairly well established, consistent approach to a federal policy on confidentiality that makes sense." Another said, "I think the federal government can facilitate some sort of framework but I don't think this can be a federal initiative." One state official suggested expanding the Health Information Security and Privacy Collaborative (HISPC), a project of the National Coordinator for Health Information Technology, which has been providing grants states to address barriers to health information exchange. Others, citing HIPAA, suggested a solution not based in an IT initiative would be a better approach.

State officials talked as much about what should not be done to improve the mutual understanding of privacy and security of health information as they did about what should be done. They very clearly indicated that federal preemption of state policies or federal legislation would be undesirable. Federal law, although powerful, was seen as inflexible. One state official said, "How long have we been talking about FERPA? We can't get that damn law changed.

Well, now the difference with HIPAA is we were able to ensure that they put a hole in it that you can drive a truck through.” One key state official, lamenting the problems with implementing federal legislation to protect the privacy or promote the exchange of public health information said:

My experience in this kind of law is that it's not static. It's something I have dealt with every week for 28 years. So, it's not something that you can just do it one time, and have it sit on the shelf. If you do that you're going to create more problems than you solve. I know it sounds easy. You do it, check it off the list, get a federal law—boom, that's it, but things are going to change and you are going to be stuck with it and a lot of the of the unintended consequences of it.

Another official said, “I really worry about new federal law in this area...It's impossible to change.” To illustrate their point that federal legislation might be more harmful than helpful, state officials cited the federal laws related to education records and substance abuse and provided examples of those laws are used to avoid reporting to state and local health departments. “I have an infirmary physician at a collect in [this state] telling that because of the federal law if he sees somebody in the infirmary with HIV infection he cannot report that to us.”

Key state officials also cited federalism as a reason for emphasizing state-based solutions to public health privacy issues. “There's very little, if any, information that's reported directly to the CDC...It's all filtered through the states, which—in a very real way that's a constitutional issue...Yes, because otherwise you're going to fundamentally re-write almost 250 years of federalism.” Other state officials were in favor of efforts to update model laws. Model laws could provide “a checklist approach to say can your state assure that you can do these eight things, regardless of how you get them done?” Another state official said, “I am not a big advocate for federal solutions to problems like this. I'm a big advocate for model state laws, if they're needed, as a better approach to getting things done.” Yet, they all seemed to agree that

bridges could be built to achieve more commonality between states. One state official, explaining this, said that “Certainly one of the things that we can do is we can start to come up with commonalities; commonalities of how we define things, commonality of how we approach things. Now is that altogether possible? No, because states and people are just too different. That said, I think we can come closer to one another.”

Federal and National Organization[‡] Key Informants. The federal officials and national public health professional organization representative who served as key informants in this study discussed privacy as only one factor, although an important one, in the broader information sharing environment. However, there were themes in their discussions around privacy and public health practice. For example, privacy and privacy-related laws and policies are an important but daily part of the bureaucratic boundaries in which federal public health professionals work. Establishing and building trust, including privacy policies that acknowledge public health professionals as stewards of data, is critical to enabling the appropriate sharing of public health information. Unlike the state officials interviewed, federal officials argued barriers to information sharing include commercial interests, information technology infrastructure, and a lack of a common framework for the privacy of public health information. Federal officials also indicated these barriers need to be addressed on a national level.

Critical need to share public health information

[‡] For the purposes of the analysis, the representative from the national association of public health officials was grouped with the federal key informants, for a total of 6 informants.

Without exception, federal officials viewed the sharing of information as a critical need and tool of public health practitioners. One interviewee said that information sharing is critical to emergency preparedness and response because “One of the biggest challenges [in public health] is the inability to know at the earliest stages of a common event where it is in fact not a common event, whether it’s in fact something that has broader national, or cross jurisdictional implications, and to respond most quickly.” Another federal official said the sharing of information is important because “Many potential interesting studies and resources are lost to us because it’s too difficult to get the data.” Still others talked about the role of information in the public’s perception of whether an event was an emergency. A federal official making reference to an incident involving a person suspected to have a form of drug resistant tuberculosis and the potential exposure of passengers on an international airline flight and questions about what information government could disclose said, “With the Andrew Speaker case, for example obviously that was—got a lot of media attention. Not all situations are like that, necessarily—get to that level or that kind of attention. But, it’s not an unimaginable sort of thing to be—to happen again.”

Interviewees talked about the need to exchange and share public health information in order to create a “picture” of public health events domestically and globally so that public health agencies would know how and where to focus their “assets,” such as personnel, research and investigation capacity, laboratory capacity, stockpiles of pharmaceuticals. In discussing the strategy to try to develop such a “picture,” one respondent said “If we can improve the picture at the community level that in aggregate, improves the picture at the national level.” Some referred to this idea as a “Common Operating Picture (COP).” Others, who expressed some

dissatisfaction with how this term was being used in multiple ways at the federal level, dismissed it as unhelpful and non-specific.

In the context of discussing the need for this picture, Interviewees discussed syndromic surveillance as one tool for maintaining an awareness of health events but expressed concern about the frequent misunderstanding by others, even those in the public health community, of the limitations of syndromic surveillance. They discussed the lack of complete geographic coverage of BioSense, a Centers for Disease Control (CDC) syndromic surveillance program and system, and the limited population covered by Essence, a Department of Defense (DOD) system. Others talked about the importance of the highly skilled and highly trained human element in interpreting and communicating the data necessary for such a picture. However, some of the officials were hopeful that by “fluxing” together a variety of existing data and information sources, this picture of the public’s health that they saw as necessary, at least domestically, could be established. Doing so would require various forms of public health information to be shared across jurisdictions.

The type of information that needs to be shared depends on the type of threat and stage of response

The federal officials who served as key informants in this study talked about how the information they need to detect and respond to public health events varies with the type of health threat and the type of response. Several of the interviewees discussed the particular information needs of public health responders to do their jobs. One respondent offered that “There are two types of data needed in a public health response—epi data and response data.” It is often the epidemiological data that contains personally identifiable health information or potentially

personally identifiable information and other information where privacy is a concern. What is needed depends on the situation. A second federal official suggested that “In a bio event... [Details about individual cases] are important because it helps you to know the characteristics of the disease. However, when it comes to something like a hurricane...I don’t think the number of deaths is nearly as relevant as the rate.”

The interviewees also indicated that the type and amount of information available also varies with the phase of the response. “We get a great deal of information on WHO alerts, CDC alerts, for things that are coming up. However, once people go into response mode, we often don’t get the more detail that we’re being asked to provide.” Sometimes that information is critical to the response. “We often can’t get the information that could have an economic impact—a poor economic impact on the hospital system, the nursing home association in that state, anything where people might choose not to utilize services.” Interviewees said that this sometimes requires interpreting a request for sensitive information using professional judgment and experience. “We’ve seen a couple of queries that are obviously based on a senior decision maker...either knowing the area really well or being concerned about specifics...asking how many beds are available at a facility. They really don’t want to know that it’s seven beds. They really want to know that the facility is 95% full and that they can handle another 5%, versus the specific value...it’s that you have to better understand what their data request is really getting at.” Interviewees talked about other examples saying things such as, “We see that all the time. How many cases of salmonella? Well, how many cases of salmonella are usually occurring in a city or any parts of this country on any given day” and the need to interpret a request for case-specific information where the data might pose privacy problems or simply be unavailable.

Privacy-related laws and policies are a part of “the bureaucracy” but they work, too

Privacy laws and policies were viewed by the federal officials as simply a part of the “bureaucracy” in which they do their jobs and many were quick to point out that other forms of sensitive information were also entrenched in a complex bureaucracy. “It’s difficult to find the correct balance between protecting individual privacy without hindering the work of public health, and I think we’re still as a nation struggling a bit to find that balance. And, we’re also stuck with the transition between primarily paper-based records and electronic health records.” Those things make it difficult to develop an approach to handling a request for sensitive data in an appropriate way.

Although privacy officers are in place in many organizations to help negotiate the balance between protecting and disclosing information, federal officials indicated that interaction between programmatic staff and privacy officers and legal counsel are not a regular occurrence. Those interactions are usually limited to issues that are controversial. “Where I end up interacting with the privacy officer is because I’m trying to establish something on a fairly high level through data sharing.” They expressed an appreciation for the expertise of their colleagues but some frustration with the privacy laws themselves. On the one hand, they said things such as “Some barriers are totally appropriate and necessary” while others reported that privacy laws and policies created real barriers to their work. (See discussion of barriers below). The interviewees also expressed varying attitudes and understanding of privacy issues. With a fair amount of confidence, one said “I don’t know of any specific law that doesn’t allow someone to talk between levels of government or cells of government.” Another, somewhat more cautiously said privacy laws are complex “which is why you need a lot of experience being able to address them.” All of the federal officials expressed a feeling of a disconnect between privacy policy and

practice on a day-to-day basis. One pointed out that “We have not yet quite achieved harmony as to the application, the appropriate application of those [legal privacy] barriers across all jurisdictions.” Several were hopeful that existing policies could serve a basis to begin to address some of those issues. Citing Homeland Security Directive 21, one federal official said “I think HSPD-21 drew a line that said from this point forward we are going to smartly work through this problem...That’s something we haven’t done in the past.”

To address privacy and security and still share information, we need “a network of trust”

The federal key informants who participated in this study felt that a balance between protecting public health information and public health practice needs could only be achieved by establishing a “network of trust.” One of the federal officials described the need for trust by saying, “The farther you lean forward, and the more you have to have a trust relationship in order to do that.” By “lean forward” the federal official seemed to mean take a proactive approach to a public health event or emerging situation that threatens health. The other interviewees expressed similar feelings that the trust relationship is what facilitates the flow of public health information. “The trust relationship that allows you to say that I don’t have any concerns that you have this information...or that allows that negotiation process to say that, well, I don’t think you need a name identifier in order to do that role.” Some of the interviewees interviewed for this study said that trust in the sharing of public health information both during an emergency and as a matter of routine requires a common understanding of privacy among public health practitioners. They also said that there is work to be done to create a common understanding. For example, one respondent said “Like the definition of privacy. What is it again? And it’s this whole concept of

how much information do you share? And so when are you actually violating privacy? Privacy might mean something different for law enforcement vs. public health vs. medical.”

One interviewee felt that, “the most senior leaders [in the United States Government] need to agree that together we will ... build a network of trust.” Interviewees were quick to provide examples of how leadership that took the wrong approach to sharing public health information could diminish trust. Most of the federal officials suggested that mandating information sharing between groups can actually reduce the level of trust, and several interviewees cited a Department of Homeland Security program known as the National Biosurveillance Information System (NBIS) as an example of such an approach. NBIS is intended to coordinate the sharing of biological information across the federal government that is being implemented in such a way that federal agencies are being required or requested to share information at a level of detail they normally would not provide to other federal agencies. Several interviewees instead said a better model to promote or develop a network of trust would be something more like an expanded version of the Biological Indications and Warnings Analytic Community (BIWAC), a relatively informal group of federal officials from different agencies that share information about potential health threats in accordance with their professional and agency requirements.

Policies and procedures about roles and responsibilities can help build that trust

Most of the federal officials who served as key informants said that there is a need for policies and procedures relating to when and how information can be shared among public health officials and with others. “It’s putting in place the policies and procedures that make people feel more comfortable that when you do share something, it’s handled responsibly.” Interviewees

differed in the degree to which they felt that policies should be explicit. One federal official suggested that the policies should be extremely explicit and require the sharing of only the minimum information necessary. Others suggested that policies could play a more facilitative role in creating the broader environment in which information is shared appropriately. “While we can agree that we need to share information and discuss what kind of information should be shared and put some business rules in place, there must be policy and processes designed so that organizations and agencies have a level of trust, of sharing the information within the partner structure...so that they’re not uncomfortable or feel uneasy that their information would be released.” One indicated that the way to achieve that was some sort of “governance” structure for data and information. However, another federal official indicated that they did not believe more policies would help at all; they thought actions of those involved in information sharing were more important than policies.

Public health professionals see themselves as “stewards” of data

One of the themes that came through very strongly in the interviews was that federal public health officials see themselves as “stewards” of data. As stewards, they manage and protect data but do not own it. The key informants expressed a strong desire for that role to be recognized and respected, or at least understood, by other professions that seek to use public health data. Their attitudes about data stewardship were explained in very pragmatic terms, as being necessary given the complex legal framework in which they work. They also said things such as “The reality is that a lot of times data sharing will always relate to personal relationships, whether there’s a policy or not.” One federal official lamented that a lack of understanding of their role as stewards and lack of opportunity to build relationships with professionals in other

sectors posed challenges. “So, it’s often that when an event happens we’re trying to create those relationships on the fly, based on previous connections and things of that sort...People often expect that we would have things like bed counts, or hospital status—overflow status, ER being overflowed, things like that—but that’s often not the case.”

They also seemed to feel strongly that the data over which they preside should be used primarily for public health and only very cautiously shared for other purposes. For example, one federal official said, “You build a relationship at the state level or local level of trust with the provider. If that information goes up to CDC and then over to Homeland Security, then, you know, you get [public health and the healthcare provider] freaking out a bit.” They cited commercial interests in health care settings as diminishing trust and conflicting with their data stewardship responsibilities.

Lack of a common language around privacy is a challenge to balancing protecting and sharing information

Overall, federal officials reported several challenges in balancing the protection of information from inappropriate use and disclosure and the need to share public health information as part of a strategy to intervene in a public health event. There was a sentiment among the key federal officials that there is a lack of agreement both within the public health community and between public health and other professions about which organizations need what types of information and for what purposes. Some federal officials felt strongly that at the federal level, there is never a need for personally identifiable information (PHI); there is only a need to know the magnitude of the event and what is going to be required to assist in the response. They explained that the states “don’t see the need for CDC to have that information

because of data stewardship issues and trust between levels of government (or lack thereof).”

Others indicated that the federal government does receive PHI in some situations. Those federal officials felt that it would be impractical and impossible to mount a federal public health response to an event without some federal officials being made aware of some PHI. One federal official summarized this conflict by saying “So there are challenges in defining...roles and responsibilities and what kinds of information should be shared and the conditions under which it should be shared.”

Interviewees also indicated that their own limited knowledge of the law is a significant challenge. They talked about how variability in state and federal agency approaches to the privacy of public health information is difficult for non-lawyers to understand. They indicated it was even more difficult to communicate to the public. However, one interviewee disagreed and said “I have not found the variability in [state] laws in an emergency to be an impediment.” That interviewee also said that “A lack of understanding that the information can be used in a constructive way and that the risks of sharing information are lower than the potential benefits” and “if people know that the law has...the flexibility in emergencies to address what needs to be addressed” it would help. The suggestion is it was a lack of understanding of the law and not variability in the law that was the primary challenge.

Interviewees also expressed that public health privacy and disclosure law leaves many questions unanswered. “When do you share, how much, is there a difference between what public health needs and law enforcement needs, how do they safeguard information, how long do they keep it, etc. What if something goes wrong?” They also felt law does not address issues that influence decisions about information sharing such as liability and redress or practical problems like second generation data sharing that are a part of their day-to-day work. One interviewee

pointed out that “Private sector entities aren’t going to be willing to share if we don’t address liability issues.” Another said “If a state continues to use a women and children food stamp program for your mothers who are low SES [Socio-economic Status], and we [the federal government] go around and ask three states that are in a hurricane-impact zone, do you still have that system in place? It’s their concern that it would show that they’re not doing their job as a public health department.” And still another federal official discussing the difficult of holding people in federal agencies accountable said, “There needs to be a vehicle for private citizens to have redress if their privacy is violated.”

Questions about sharing data that another program or federal agency provided, sometimes referred to as second generation data sharing, come up often in interviewees’ work. In trying to convey the seriousness of this issue, one federal official said “When our agency gets information how we share beyond our agency is of equal importance to the entity giving it to us as how use it ourselves.” One interviewee said, “The salmonella outbreaks are a good example because Homeland Security was looking for information and FDA and CDC are running an investigation trying to figure out what’s going on.” The interviewee explained that while sharing some of the request data or information did not pose a problem, there were concerns about sharing information that was proprietary about the source of the outbreak, private patient information, or might lead to legal action that would make continuing the epidemiologic investigation difficult. Interviewees indicated that law provides them with little guidance—

The issue of second generation data sharing is a frequent problem, even if it’s going to be de-identified, and we, under existing guidance and laws, usually can’t share that data even though we would be an essential and efficient source of it to other groups... We have to send them back to get the component from the data owner and the other component from the different data owner, etc.

Another tried to make light of how much work trying to understand and comply with the relevant law can mean in any particular situation by saying “[Second generation data sharing challenges] can always be overcome if the person can live long enough, fill out all the forms, and survive the bureaucratic process.” Still a third federal official suggested that most legal guidance is of little help when the unexpected happens.

Federal officials also viewed information technology (IT) as a possible tool for improving the sharing of public health information and the protection of privacy with a degree of caution. One federal official said, “There are technology solutions that could improve around the edges of information sharing, but I generally have experienced that the technology solutions are easy once there’s an agreement about what, when, and how to share.” Some of the Federal officials were skeptical about how technology could help to improve sharing and the protection of privacy when there is basically “...No IT infrastructure in state and local public health.” “There just needs to be more IT investment at the state level and they just don’t have the money to do it, essentially.” “One of the issues right now is, you know, the federal government doesn’t have to balance a budget but the states and local governments do.” They also expressed mixed feelings about IT in general and some saw it as a potential threat. “It’s very hard to for health officials to invest in IT. Sometimes public health people see themselves as being replaced by the IT thing, whatever it is.”

Some federal officials thought more IT might create a greater challenge to privacy. “You can do almost anything with data; no data is totally safe or de-identified.” Others interviewees felt that IT would be helpful but were skeptical about getting to that on a nationwide basis, point out that “Most of the military installation level sharing of data with state or local health

departments is non-electronic in nature” while “Almost all of the data DOD and VA send and receive and exchange with each other is electronic.

Summary of Results

Privacy is an important issue in public health practice. Key findings from my research include:

- There is a critical need to share public health information within public health and across jurisdictions;
- State-Federal public health information exchange is a voluntary, but complicated, relationship;
- The type of information that needs to be shared depends on the type of threat and stage of response;
- The decision to disclose or not disclose is an important one for state public health officials;
- Public health professionals see themselves as “stewards,” not owners, of data and information;
- Lack of a common language around privacy is a challenge to balancing protecting and sharing information;
- Privacy-related laws and policies are a part of “the bureaucracy” but they generally serve their purpose;
- If you have seen one state privacy law, you have seen one state privacy law;
- There are opportunities to create new state public health policies to better balance privacy and disclosure;
- State public health privacy policy have developed “organically, not logically;”

- To better address privacy and security and still share information, we need “a network of trust;” and,
- Policies and procedures about roles and responsibilities can help build that trust.

State public health officials, especially, strongly recognized the need to protect privacy.

In discussing privacy and disclosure issues in their work, state and federal officials discussed three aspects of privacy: 1) the physical protection of an individual person’s or aggregated set of potentially or actually identifiable health information; 2) decisions about whether and to what extent information acquired by public health officials should be treated as private, protected, or confidential; and 3) decisions about to whom and when public health information about individuals or groups should be actively shared or disclosed. However, public health officials use terms such as privacy, confidentiality, protecting information, sharing, disclosure, release in a variety of ways, some incorrect, suggesting that there is a lack of common language within public health for issues related to privacy.

The analysis of state public health laws suggested that despite much work over the past decade, including the development of model state statutes and convening a collaborative to modernize state public health laws, public health privacy laws exist in few states, are unclear, and do not reflect provisions recommended by experts in the field. Interviewees report that where there has been change in state laws, it has been driven by notable public health events, such as the emergence of HIV/AIDS and the anthrax attacks in the fall of 2001, but the state law analysis revealed that the changes have not necessarily been made in a logical way and the resultant laws do not always offer public health practitioners the flexibility they need. However, some interviewees reported that their current state laws do generally allow for the protection of privacy *and* disclosure as needed, or they have found ways to work within the confines of the

laws. I found that there is a gap between how the public health leaders interviewed for this study understand the privacy, protection, and appropriate sharing of public health information and current state laws. Through the statutory analysis, I found that while the laws may offer public health officials some flexibility, existing state laws are very limited, incomplete, not clear, antiquated, and difficult to interpret. The laws may be subject to various interpretations and the different approaches to different types of disease information means there is not a single adequate approach to the protection of public health information. These findings suggested that federal and state officials are accurate in their views that state laws may not be sufficient in the future given developing technology, the development of electronic health records, prolonged or severe public health emergencies, and in light of a growing population and shrinking budgets for public health.

Through the interviews, I also learned that state officials are concerned with how decisions about the disclosure or release of information often must be made at the state level on a case-by-case basis, which is inconvenient and expensive. They also raised questions and concerns about ownership and use of public health data outside their jurisdictions, regardless of the user, but especially Homeland Security and law enforcement and the media. State officials cited the need for changes to state laws or other approaches to address privacy issues if federal policies promoting the inter-jurisdictional and interdisciplinary sharing of information were fully implemented. Given Constitutional law and federalism, state officials expressed strongly negative impressions of potential approaches that might involve federal legislation mandating or somehow preempting state control in this area. They also had a variety of opinions as to whether model laws were useful and whether the language in existing model laws aligned well with their understanding of how they protect and disclose data, during an emergency or otherwise.

Federal officials, who work primarily with aggregated data from the states and sometimes with personally identifiable health information, are more concerned with the flow of information and ensuring it reaches the public health professionals who need to make evidence-based decisions about public health interventions. Interviews with federal officials and national partners suggest that recent federal policy developments promoting the sharing of public health information are viewed as needed but that there are considerable challenges to successful implementation. At the same time, federal officials were divided in their concerns about including the Department of Homeland Security in the flow of public health data or information.

Both federal and state officials indicated a need to build a network of trust among those that do need to share public health information. Both groups also acknowledged that the lack of uniformity in laws and practices related to the acquisition, use, and storage of public health information breeds disagreement and inhibits trust. Those inconsistencies are also a source of confusion for a variety of stakeholders. The interviewees stated that privacy law would be more useful to them if it acknowledged issues such as the role of public health as stewards of data, the need to share data freely among public health professionals, and the need for flexibility and professional judgment in determining when to disclose data to protect the public's health.

Based on the interviews with federal and state officials, it seems reasonable to conclude that there are opportunities to remove privacy policy barriers to public health practice and to create a more consistent policy environment that is driven by the science and professional judgment of public health leaders around the appropriate disclosure of public health information within public health, with public health partners, and with the public. Both state and federal key informants seemed to suggest that changes in both policy and practice around informational privacy may be needed to enable the movement toward public health data collection at the source

of patient care, a whole patient approach to public health practice, and the use of information technology in public health practice. However, the interviewees also indicated that an essential precursor to deciding what changes should be made to state public health privacy laws is a common understanding of what ideal privacy practices and policies should accomplish. In other words, the interviewees thought that before anyone tries to change state laws or develop a model law, there was a need to build consensus around when the privacy of information under the control of public health officials should be maintained and what criteria would justify disclosure. I agree and in the next chapter describe an approach to developing a better shared understanding of how to protect the privacy of public health information while allowing for appropriate disclosures when needed to protect the public's health.

PLAN FOR CHANGE

The purpose of this dissertation research was to better understand state public health privacy laws and whether those laws offer public health practitioners the flexibility they need in their work. The preceding chapter describes a need to develop a mutual understanding among public health professionals about how to protect the privacy of public health information. The key informant interviews conducted for this study suggested that public health practice is predicated on trust that information provided to public health officials or exchanged among various governments will be: 1) used for public health purposes; and, 2) disclosed to the public or others only when absolutely necessary to protect health and safety. Results from the policy analysis demonstrate that state laws, while adequate, do not completely address practical public health issues related to privacy and disclosure of public health information. Together, these results suggest that the development or maintenance of that trust may not be adequately addressed in existing public health policies.

To the extent a common understanding of how public health information possessed by health officials should be protected does exist, the principles are not well-developed enough to communicate to public health partners, such as law enforcement. To address this need, I propose the development of a national framework for the protection of public health information. The term “framework” is intentionally broad. It is intended to imply a common approach across jurisdictions and levels of government to protecting the privacy of public health information while still allowing that information to be used to achieve public health purposes. I propose a

framework rather than a model state law for several reasons. First, a framework lays out the principles, rather than suggested statutory language, and I believe that reaching agreement on the principles is more valuable than proposing model language. Second, a model statute presumes the same need for statutory language across all states while I found that states take different approaches; some rely on statutes while others rely on regulations. Finally, establishing a set of principles without model statutory language places the emphasis on the substance, rather than the phrasing, of state laws.

Components of a National Framework

The purpose of the framework would be to promote a common understanding of desirable principles and practices related to privacy, security and disclosure of information possessed or controlled by governmental public health entities. One of the fundamental questions that must be answered in the development of the framework is whether disclosure ever an acceptable disease control measure or necessary to carry out another control measure. Another question that must be answered is around whether it is possible to develop a framework that takes an all-hazards type of approach or is separate treatment of certain types of disease information necessary. The process of creating this framework may contribute to the development of consensus among the various stakeholders on the principles that should be applied to the privacy, protection, and disclosure of public health information.

Through the research conducted for this study, I identified key principles for inclusion in the framework including: consent; minimum necessary; disclosure at the level data were collected; continued protections in times of emergency; and, discretion of state and local health officials. Consent for disclosure of potential or actual personally-identifiable information should

be sought from the individual or group of individuals that the information is about whenever feasible. Reflecting the “minimum necessary” ideal expressed by participants in the key informant portion of this study, the framework might also convey that while data and information about risks to public health should be as transparent as necessary, only the minimum amount of personally identifiable information necessary from a scientific perspective to convey events and risks should be disclosed to public health partners or to the public. In addition, another principle to be reflected is that data disclosure is preferable at the level of government at which the data were collected; in other words, if a state health department collected the data, the state health department, not a federal agency, should make the determination regarding disclosure. To ensure continuity of protections in times of emergency or uncertainty, individual persons should have available the same informational privacy protections in times of both public health emergencies and non-emergencies. And, requests for disclosures of public health information, whether personally identifiable or not, should be subject to the professional judgment of public health officials.

The framework should also describe ideal practices for the protection of public health information. These practices might include: 1) the avoidance of unnecessary information collection; 2) methods for de-identification of data; 3) criteria that trigger the disclosure for public health purposes; 4) criteria that trigger or permits disclosure for law enforcement purposes; and, 5) criteria for disclosure when a third party’s commercial interests are involved. For example, personal identifiers should be collected or maintained by public health only where there is absolute public health, health-related research, or vital records necessity. Data and information about an individual or group of individuals should be de-identified whenever possible to avoid the identification of individuals or stigmatization of groups. Disclosure or

sharing of personally-identifiable health information or aggregate community-level data should take place to further or achieve a public health or health-related research purpose. The framework should provide criteria that can be used by a health official as a guide as to what is a public health or health-related research purpose. As the results of this study also suggest, criteria for disclosure or sharing of personally-identifiable health information with law enforcement or for other HIPAA-permissible disclosure purposes would be helpful. And, it should provide that consent is preferable for disclosure where the commercial interests or needs of third parties are involved, such as where there legal action and the data might be discoverable during a litigation process.

Development of the Framework

Ultimately, the content of the framework should be developed through a consensus process involving a representative group of stakeholders convened or championed by a public health professional organization, such as Association of State and Territorial Health Officials (ASTHO), CDC, or a high-level coordinating office, such as The Office of the National Coordinator for Health Information Technology (ONC) or an office within the White House.

There are many stakeholders in questions about the privacy and security of public health information. The development of this proposed framework should involve stakeholders from the following sectors, fields, or organizations: healthcare delivery; health information technology; health insurers; news media; private sector employers; state, local, tribal and territorial public health; privacy advocates; law; patient advocacy (e.g. HIV or tuberculosis patient organizations); religious organizations; and vulnerable population treatment and advocacy (e.g., National Alliance for Hispanic Health). Public health professional organizations such as the American

Public Health Association, Association of Public Health Laboratories, Association of State and Territorial Health Officers (ASTHO), Council of State and Territorial Epidemiologists (CSTE), and National Association of County Commissioners and Health Officers (NACCHO). In addition, the following federal agencies would be key stakeholders in the development of the framework: HHS's Assistant Secretary for Preparedness and Response, CDC, Department of Homeland Security's Office of Health Affairs, Department of Defense's Health Affairs and Northern Command, Department of Justice, Food and Drug Administration, and USDA. If convened by the federal government to develop recommendations, this group of stakeholders would likely be covered by the Federal Advisory Committee Act, which imposes requirements on bodies that provide the recommendations to the federal government. The group established could make recommendations regarding the content of the Framework to be released in a government report or other document.

There are several emerging and intersecting policy streams or interests at the national level that suggest a window of opportunity to convene a group of stakeholders to develop the Framework. The first stream is the health reform agenda being carried out by the current administration.¹⁴⁵ This agenda includes a commitment by the Obama administration to the work on health-related information technology and an initiative to create a nationwide infrastructure for electronic health records. The second stream is the emergence of Novel H1N1 Influenza, which focused the attention of the White House and high level executive branch offices on the needs of public health.¹⁴⁶ The third stream is changes within Homeland Security policy¹⁴⁷ and the continuing interest in the Department of Homeland Security in creating a public health "information sharing environment" (ISE). ISE a term used in the intelligence sector to describe "A trusted partnership... in order to detect, prevent, disrupt, preempt, and mitigate the effects of

terrorism against the territory, people, and interests of the United States by the effective and efficient sharing of terrorism and homeland security information.”¹⁴⁸ The current political focus on reforming the United States health system, also, seems likely to result in increased scrutiny on collection and use of health-related data by the federal government. Taken together, these streams suggest there may now or soon be a critical mass of interest at the national level to generate action that might further one or more of these initiatives of the Obama administration.

Alternatively, the framework could be promoted on a more grassroots level from within existing initiatives sponsored by the federal government and that involves many of the relevant stakeholders, such as the Federally-sponsored Health Information and Security Privacy Collaborative (HISPC), a project of ONC. Or, the framework concept could be conducted with only limited federal involvement through a public health professional organization, such as ASTHO, NACCHO or CSTE. These organizations typically rely on funding from CDC to conduct specific projects such as the development of a framework but have the capacity to carry out much of the work, including convening stakeholders, developing content and communicating policy and program development needs. Ultimately, however, the involvement of federal agencies is necessary to the successful development of the framework because they are key stakeholders in the protection and exchange of public health information.

Regardless of whether support for development of the framework comes from the highest levels of government or it is a grassroots effort (or both), communication will be critical to the implementation of the framework. Communication with stakeholders, especially state and local public health about the need and rationale for the framework will be essential and can be accomplished through the public health professional organizations and other informal networks of public health professionals. Communication through engaged public health officials with

federal policy makers as well as with state policy makers regarding implementation needs will also be important. And, communication with the public and other stakeholders via public health partner organizations that often engage in these kinds of communications efforts via the news media, print, and education campaigns, although less critical, will still be necessary.

Opportunities for Implementation and Need for Policy Change

The purpose of developing the framework is to build consensus, establish a dialog, and engage stakeholders in a discussion about common principles and practices in protecting public health privacy. Part or all of the approach may ultimately be memorialized in law or regulation. Given the concerns about federal legislation expressed by the key informants who participated in this study and for Constitutional reasons, federal legislation would not be the ideal means to begin to implement or enforce the principles adopted in the framework. Instead, legislative change based on the principles in the framework should occur at the state level, depending on the needs of each state. In other states where no legislative change is needed or where no legislative change is feasible, the framework might be used to change practices and procedures within health departments.

Although key informants interviewed for this study suggested federal legislation would not be desirable, several did suggest that there might be a role for the federal government in developing the framework. These roles might include facilitator of state policy change and encouraging common practices in protecting public health information. Although there mixed opinions about model laws, a few of the interviewees suggested the federal government in addition to convening the group that would develop the framework could also convene groups to revise the existing model state public health laws. Others, concerned that models create a

misleading standard, suggested that the federal government create a “checklist” or measurement model be created for states to evaluate their state privacy laws against, using principles from the framework. Existing model acts, which were created almost a decade ago for distinctly different purposes, may not strike the desired balance and all of the technological factors relevant to public health practice today. It was suggested by one informant that HISPC be used to develop such a model or checklist. One state official argued that the development of such a model was an appropriate role for CDC.

One key informant suggested CDC establish a best practices-type of project for the sharing of public health information under which states could be funded to design and replicate best policies and practices associated with the protection and exchange of public health surveillance data. Another suggestion raised by one key informant was to establish federal policies that encourage the adoption of agreements between states. Interviewees suggested an approach similar to the development and implementation of the Emergency Management Assistance Compact (EMAC), an interstate compact with a governance structure funded by federal dollars that enables states to assist each other during times of emergency. Federal legislation helped to establish the EMAC. Yet another role suggested for the federal government was funding of additional research around the need for, and value of, disclosure of particular types of public health information. Such research would require federal funding, although not necessarily legislative change. At the agency level, the development of new CDC policies related to privacy and data use or revisions to the CDC policy on the re-release of data might flow from or help to implement the Framework.

Future Research Opportunities and Evaluating Implementation of the Framework

Ultimately, the framework, or any effort to develop or implement a common understanding of public health privacy and disclosure would need to be evaluated. The evaluation plan would need to include different approaches to various aspects of the overall effort. This study, in a sense, serves as a formative evaluation for the framework concept. If an effort to develop the framework were implemented process and outcome or impact evaluations would also be needed. For example, if a FACA is utilized to develop the framework, process measures might be used to assess whether the FACA mechanism engaged all the appropriate stakeholders and developed a framework. If a model act or checklist is used to implement the framework, the outcomes would be appropriate to assess. Outcomes measured might include how many states implemented what aspects of the recommendations in the form of changes to state laws. An impact assessment would be the ideal way to measure the impact of the framework development and implementation effort on information exchange among state and federal partners. These types of assessments are challenging to conduct due because it is difficult to control for confounding factors, such as changes in leadership, concurrent policy change, and changing budgets. Before, during, and after development and implementation, the framework would present opportunities to examine issues such as the demographic covariates associated with certain types of privacy and information sharing policies and practices across states in order to better understand what conditions facilitate the desired outcomes.

DISCUSSION

There is a gap between how the public health leaders interviewed for this study understand the need to protect the privacy of public health information and the state and federal policies that currently address this issue. This gap has many significant ramifications, including that the lack of a consistent approach to public health privacy across jurisdictions may be a barrier to achieving objectives that are essential to improving health and public health practice in this country. For example, it may be a barrier to the establishment of electronic health records, the implementation of the reform of the health system in this country to integrate prevention and acute care, and the implementation of a nationwide public health surveillance infrastructure to provide early warning of emerging or changing threats to human health such as pandemic influenza. There is also a second significant gap between the how the public health leaders interviewed for this study understand the need to protect the privacy and security of public health information and existing model laws intended to influence the development of state laws. State officials interviewed for this study indicated that model public health laws have been influential in drawing attention to the problem of inadequate state laws but the provisions have generally not been adopted by states.

As one means to begin to fill these gaps, a plan to develop a set of common principles, a framework, around the privacy of public health information is proposed in the previous chapter. The rationale for proposing that change should begin with a framework as opposed to a new

model law is that through conducting this research, it became clear that there is a need for additional consensus and thought within the public health community about what privacy protections are necessary and appropriate for public health information and what policies would only create additional barriers to public health practice. The framework, as conceptualized in this study, could later, be implemented through changes in policy at the local, state, and federal levels as well as the dissemination of model laws and best practices across the public health community. Depending on the principles reflected in the framework, each state would have to review its existing laws and develop statutory language that best implements the principles within its statutory and practice schemes. For example, in states where public health is centralized at the state level, the statutory scheme might look very different from states with local control of public health. Model language or other approaches to encouraging or facilitating state policy changes that reflect the agreed upon principles can be developed with relative ease as a method of communicating the goals and ideas about how to best protect privacy.

The recommendation to start with a framework or set of principles rather than a model law is also based on a recognition that more policies, regardless of whether the policies influence activities or programs indirectly or whether the policies have the force of law, are not always better for public health practice. Even where the weight of the evidence of the benefit of policy change for health outcomes is profound, such as in tobacco control and injury prevention, there remain many questions and disagreements about the unintended consequences of “too much” policy or policy schemes that are less than ideally suited to achieve the intended outcome. These considerations need to be balanced with the fact that development of policies, even imperfect policies, can help to create consensus or a mutual understanding that serves as the tipping point for actions that lead to the intended outcome. For example, in tobacco control, when a smoke-

free indoor air ordinance is introduced in a community, even if the policy change effort is not successful, the dialog that is created in the community around making tobacco use a non-normative behavior has been shown to have a measurable effect on tobacco use.¹⁴⁹ And, it is a generally accepted legal principal that where policies are clearly articulated, plainly worded, and easily understandable, the likelihood of a common interpretation of those policies is increased.

I contend that the development of a set of principles related to the privacy and security of public health information that reflects the balance between the need to protect information and disclose it could have a lasting impact on both public health policy and practice.

Recommendations from Federal Advisory Committees and other panels that have attempted to address moral or ethical challenges in health been recognized as having a lasting impact on practice and policy. For example, the National Bioethics Advisory Commission and its precursor entities, issued the Belmont Report, which dramatically impacted the way researchers think about and conduct human subjects research and resulted in federal legislation that translated principles into practical requirements.¹⁵⁰ Even more recent and less prominent efforts to outline common principles for public health, such as the Public Health Leadership Society's Principles of the Ethical Practice of Public Health,¹⁵¹ have arguably at least helped to draw attention to particular issues.

It is true, however, that the most well-known and impactful of such efforts were developed at least in part as a response to a real or perceived public health crisis. And, it is not really clear if there is a profound enough crisis within the tension between information sharing and privacy to lead to the pursuit of the framework or a similar initiative. It is possible that a situation similar to the purported disclosure by federal officials of the name of an airline passenger with extremely drug resistant tuberculosis to the news media in the context of the

currently emerging influenza pandemic could open an obvious policy window. Beginning a dialog before such an event would increase the likelihood of utilizing that policy window when it is open.

The relationship between the development of the framework proposed here and the health impact or outcomes is not proximate in the way that, for example, counseling members of at risk populations about unhealthy behaviors can be quantified and the counseling activity can be linked directly to improved outcomes. The development of a set of principles, instead, supports other critical public health activities including public health surveillance, biosurveillance, and public health emergency response and recovery operations. This distal relationship might cause some individuals to be critical of the potential value of addressing the privacy and security of health information. While there is some value in pursuing only initiatives and approaches that themselves lead to a demonstrable impact on health, there is a competing, and perhaps more pressing, need to give some consideration to the social structures and assumptions that underlie public health practice itself.

Assuming the development of a set of common principles related to the privacy, protection, and appropriate sharing of public health information by CDC or one of the other organizations described in the previous chapter is both a worthwhile and feasible approach, the question then becomes how likely is it to happen? Creating major change of any type is not easy. There are innumerable theories on how to create change. For example, Harvard Business School Professor John Kotter details a process with eight stages: 1) establishing a sense of urgency, 2) creating a guiding coalition, 3) developing a vision and a strategy, communicating the change vision, 4) empowering broad-based action, 6) generating short-term wins, 7) consolidating gains and producing more change, and 8) anchoring new approaches in the culture.¹⁵² Jim Collins, a

former Stanford University professor, describes “getting the right people on the bus,” “level 5 leadership,” and “turning the flywheel” as means to create change.¹⁵³ Both are excellent approaches. Certainly establishing momentum by getting the right people involved early in the development of the Framework would be critical as would developing a vision and a strategy. However, no single theory completely describes what would be required to create and implement the Framework.

At present, much of the public health system faces tenuous circumstances, including budget cuts, furloughs, shortages of critical personnel, and the exhaustion of resources. With these challenges, it is difficult to make the case for new efforts of any kind, particularly one that may not appear to have an immediate impact on health outcomes. Still, there is an urgent need for public health to clarify state privacy laws in order to enable the flow of public health surveillance data and information among the states and between the states and the federal government. States and CDC must have the capability to quickly collect, analyze, and use the necessary data to track the spread of the H1N1 influenza virus, identify changes in the characteristics virus, and understand the efficacy of the vaccine. Less immediately but still importantly, there is a need to resolve privacy law conflicts that prevent public health from developing interoperability in surveillance systems across jurisdictions to enable detection of a bioterrorism event or an emerging infectious disease. Current approaches to disease surveillance may not identify disease events in time for interventions to work effectively.

There are several specific actions that could lead to the development of the Framework. These include:

- A formal process evaluation of the sharing of information among federal agencies engaged in pandemic H1N1 influenza;

- Development of advice to states related to the implementation of the reporting requirements of the International Health Regulations and the related privacy and security considerations;
- Development of target capabilities for federal, state, and local public health agencies and Emergency Response Function 8 partners for the sharing of epidemiologic information that includes sub-capabilities related to privacy protections;
- Requiring CDC programs receiving Terrorism Preparedness or Emergency Response or Influenza funding to collaborate in a dialog around the development of a set of common privacy and information sharing principles;
- Providing states receiving Public Health Emergency Preparedness opportunities to collaborate on the development of the Framework and technical assistance with implementation;
- Developing a measurement model for state information sharing and privacy protection policies and reporting on state progress;
- Conducting an exercise involving multiple federal agencies that specifically addresses information sharing; and
- Engagement of civil liberties and patient rights stakeholder organizations in public health future preparedness exercises and a post-exercise debriefing with those organizations to develop a mutual understanding.

Through the approaches and opportunities for change listed above, public health can begin to address some of the mechanics of creating privacy laws that provide public health practitioners the flexibility they need. However, the intersection of privacy and public health is

really an intersection of competing value systems. If public health is to really achieve its full purpose of community engagement, we should seek to engage in the development of privacy policies and view privacy issues as an opportunity and a means, not a barrier, to action.

APPENDIX A. KEY INFORMANT INTERVIEW RECRUITMENT EMAIL

Dear Colleague,

You are a public health leader who is familiar with the challenges and opportunities related to the balance between maintaining the privacy and confidentiality of public health records and sharing those records for public health purposes. I am a student in the Executive Doctor of Public Health program at the University of North Carolina at Chapel Hill working on a research study related to this issue. The purpose of the research study survey is to evaluate the impact of state public health laws on information sharing among public health leadership within states and between the states and the federal government.

As part of the study, I will be conducting key informant interviews. As a leader in this issue, your participation is requested in an interview during the week of February 9, 2009. Participation in the study is entirely voluntary and will be confidential. The study has been approved by the University of North Carolina IRB. For the interview, I will ask you a series of questions about your ability to share information and your opinion on state public health laws as they relate to the ability of health officials to share information. The interview will last about 60 minutes. There are no benefits to you for participating and the only risk to you would be disclosure of your identify; however, because I will not record your name with the interview notes and the notes will be kept under lock, that risk is minimal. Approximately 20-25 participants will participate in the interview portion of this study. The results from all of the interviews will be aggregated in such a way that you will not be identifiable.

Later this week, I will contact you by telephone to ascertain your willingness to participate in an interview. If you are unable or unwilling to participate but could suggest an alternate person in your organization, such as your privacy officer or your general counsel, that I could contact, that would be appreciated. I look forward to speaking with you and please do not hesitate to ask me any questions you may have regarding the study. Thank you very much.

Sincerely,

Jean O'Connor, JD, MPH
Candidate for the DrPH degree
University of North Carolina at Chapel Hill
Email: jco@email.unc.edu
Phone: 404-285-1300

IRB # 08-2022

APPENDIX B. STATE KEY INFORMANT INTERVIEW DISCUSSION GUIDE

1. Could you please tell me about what your roles in the health department?
2. I would like to learn more about how your state addresses privacy. Can you tell me about any programs or other officials in your state or others that you commonly interact with that are involved in privacy issues related to public health?
3. What are some of the current issues your state is facing in health-related privacy?
4. Can you give me an example of dilemma or challenge related to the privacy of health-related information you have faced in your state?
5. I am in the process of researching state health-related privacy laws. Can you characterize your state privacy statutes for me as well as any major recent developments in case law?
 - a. How does your law treat acquisition, use, and disclosure of health-related information by the health department?
 - b. Do your state statutes meet the needs of the health department?
 - c. Do you think they meet the needs of individuals?
 - d. What about health care providers?
 - e. Does your state law allow for dual use of public health data or information? In other words, sharing of information collected for public health purposes for other purposes, like law enforcement.
 - f. Are there any holes or gaps in your state privacy laws that you would fill if you could?
6. How did your state privacy statutes come to look the way they way do? For example, did your state adopt model legislation or is there a particular interest group or lobby that played an important role in shaping your law.
7. Tell me about how privacy practices, beyond the requirements of the letter of the law, are carried out at your health department? How is training of staff, enforcement of policies, and corrective action taken?
8. Federal officials sometimes hear that privacy considerations are a reason states are reluctant to share data. What do you think about that?
9. There are several federal initiatives related to connecting public health surveillance systems to speed the reporting of health-related information from health care providers to the federal government for earlier detection of public health events. What privacy issues, if any, would something like this raise for your state?
10. Would you have any reservations about data or information you reported to one federal agency being shared with another? What about if it did not have personally identifiable health information?
11. Are there are resources or activities that you think are needed to improve the protection of public health information (or allow the sharing of more health information) at your health department or within your state? At the federal level?

APPENDIX C. FEDERAL KEY INFORMANT INTERVIEW DISCUSSION GUIDE

1. Please tell me about your role with your agency or organization?
2. What type (state, federal, local) of organization do you work for?
3. Describe your responsibility within that organization?
4. Tell me about the data or information about disease outbreaks, health conditions, or things affecting human health in your jurisdiction that you work with?
 - a. Case reports? If yes, are those laboratory-confirmed cases?
 - b. Information about epidemiologic investigations?
 - c. Can you please provide an example?
5. How do you use the public health information you work with?
6. Do laws, regulations, or other types of policies affect, positively or negatively, your ability to share public health-related information either with state public health officials or with other federal public health officials? Please tell me about that.
7. Tell me about your knowledge of the laws and policies in your jurisdiction that pertain to what public health information you should share and when.
 - a. Are you confident in your knowledge of the laws and policies?
 - b. Are there aspects of the law that you wish you understood better?
8. As you know, there are several federal initiatives related to improving the sharing of information for response. Where do you think those initiatives are headed? Why?
9. What are the barriers to achieving success in some of those initiatives?
 - a. Information technology?
 - b. Privacy issues?
 - c. Use of information issues?
10. Is there any specific law or policy that you think needs to be changed to improve your ability to share public health information with relevant groups?
11. Is there anything else you would like to add?

APPENDIX D. KEY INFORMANT INTERVIEW TELEPHONE CONSENT SCRIPT

Hello, my name is Jean O'Connor. I am a DrPH student at the University of North Carolina at Chapel Hill; I'm conducting a study about state public health laws and how they affect the sharing of information among public health leaders. Specifically, I am interviewing members of the Homeland Security Presidential Directive-21 BioSurveillance Working Group and state public health leaders. Your participation in this study is completely voluntary, meaning you do not have to participate unless you choose to do so.

Would you be willing to answer some questions to help me determine if you are eligible for this study?

(If person says no, thank them for their time and that they are not eligible for the study. If they answer yes, proceed)

Thank you. Do you participate in the HSPD-21 Working Group or are you a state health official?

(If person says no, thank them for their time and that they are not eligible for the study. If they answer yes, proceed)

Thank you. The purpose of this research study survey is to evaluate the impact of state public health laws on information sharing among public health leadership within states and between the states and the federal government. We estimate that approximately 13 participants will participate in the interview portion of this study. For the interview, I will ask you a series of questions about your opinion on the status of state public health laws as they relate to the ability of health officials to share information. This should take about 60 minutes. You do not have to answer any of the questions. If that is the case, we will skip that question and go on to the next one.

All the information I receive from you by phone, including your name and any other identifying information, will be strictly confidential and will be kept under lock and key. I will not identify you or use any information that would make it possible for anyone to identify you in any presentation or written reports about this study. If it is okay with you, I might want to use direct quotes from you, but these would only be quoted as coming from "a person." When all the interviews have been completed, I will analyze the results and present them in aggregated form. I will not identify individual participants.

The only risk to you associated with participating might be if your identity were ever revealed. However, I will not even record your name with your responses, so this cannot occur. There are no other expected risks to you for participating. There are also no expected benefits for you either.

This study is unfunded. This study is being conducted to complete the dissertation requirement for a DrPH at the University of North Carolina at Chapel Hill. My Chairperson is Dr. Tom Ricketts, a Professor in the Department of Health Policy and Administration.

As you know, all research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, you may contact—anononymously if you wish—the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Do you have any questions?

Do I have your permission to begin asking you questions?

It would be helpful to me for the purposes of taking notes if I could record our conversation. Do I have your permission to audiotape this interview? I will erase the taps after my notes have been transcribed.

(If person says no, thank them and let them know the recorder is not on. If they say yes, thank them and let them know the tape is now on.)

IRB #08-2022

APPENDIX E. STATUTORY ANALYSIS

State	General Provisions	Exceptions to Use or Disclosure			Exceptionalism			MSHPA Provisions			MESHPA		CITATIONS
	Presumption of non-disclosure	De-identified for statistical analysis	Contact tracing/partner notification	Protect public health	HIV	STDs	Other conditions	Public record	Permits disclosure to federal authorities	Secondary disclosure	Suspect BT cases disclosed to law	Other disclosure to law enforcement	
	PRESNONDIS	EXRESEARCH	EXCONTRACE	EXPROPH	ISMHIV	ISMSTD	ISMOTH	MSHAPUB	MSHPAFED	MSHPASECOND	MESHPABTLE	MESHPALIMLE	
AL	1	0	0	1	0	0	1	0	0	0	0	0	AL ST 22-11A-2; AL ST 22-11A-38; 22-11A-9; AL ADC 420-4-1-.07; AL ADC 420-4-1-.08
AK	1	1	1	1	0	0	0	0	0	0	0	0	AK ST 18.15.355; AK ST 18.15.360; AK ST 18.15.362; AK ST 18.15.365
AZ	1	1	1	1	1	0	1	0	1	1	0	0	AZ ST § 36-664
AR	0	0	0	0	1	0	0	1	0	0	0	0	AR ST § 20-15-201, § 20-15-904, § 25-19-105, § 25-190193(5)A
CA	0	0	1	0	1	0	0	1	0	0	0	0	Cal. Health & Safety Code § 120260.5, § 120262, § 120975, § 120980, § 121010, §
CO	0	0	0	0	1	0	1	1	0	0	0	0	CO ST § 25-4-1405.5, 25-4-511
CT	0	0	0	0	0	0	1	1	0	0	0	0	CT ST § 19a-262; § 1-200, § 1-210(b)(2)
DE	1	0	0	1	1	0	1	1	1	1	0	0	16 DE ST § 1203, § 1224, § 1232, § 2005
DC	1	1	0	1	0	0	0	0	0	0	0	0	DC ST § 7-131
FL	0	0	0	0	1	1	0	1	0	0	0	0	FL ST § 384.25, § 384.26, § 384.29, § 119.011(11)
GA	0	0	0	0	0	1	0	1	0	0	0	0	GA ST § 31-17-7, § 50-18-70(a)
HI	1	0	0	1	1	0	1	1	0	0	0	0	HI ST § 325-4, 325-73, 325-101, 626-1
ID	0	0	0	0	1	0	0	1	0	0	0	0	ID ST § 39-610, § 30-14-607
IL	0	0	0	0	1	0	0	1	0	0	0	0	410 ILCS 305/2; 140 ILCS 513/30(7)
IN	1	1	1	1	0	0	0	1	0	0	0	0	IN ST. § 16-41-8-1, § 16-41-10-2, § 5-14-3-2
IA	0	0	0	0	1	0	0	0	0	0	0	0	IA ST § 141A.9
KS	1*	0	0	1	0	0	0	1	0	0	0	0	KS ST § 65-102b; § 65-118, § 65-119, § 45-0217
KY	0	0	0	0	1	1	0	1	0	0	0	0	KY ST § 214.181, § 214.420, § 61.870
LA	0	0	0	0	1	0	0	1	0	0	0	0	LSA-R.S. § 40:1300.14, § 44:1(2)
ME	1	0	0	1	1	0	0	1	1	1	0	0	22 ME ST § 808, § 824; 5 ME ST § 19201, 32 ME ST § 16607(2)
MD	1	1	0	0	0	0	0	1	0	0	0	0	MD Code, Health - General, § 4-102; MD Code, State Govt. § 10-611
MA	0	0	0	0	0	1	0	0	0	0	0	0	MA ST 111 § 119
MI	0	0	0	0	0	0	0	1	0	0	0	0	MI ST § 15.442
MN	1	1	0	1	0	0	0	1	0	1	0	0	MN ST § 13.01 et seq., § 176.234, § 144.0525, § 144.4813
MS	0	0	0	0	1	0	0	1	0	0	0	0	MS ST § 41-23-1, § 25-611-1
MO	0	0	0	0	1	0	0	0	0	0	0	0	MO ST § 191.657, § 575.010(9)
MT	1	1	0	1	1	1	1	1	1	1	1	0	MT ST § 50-16-702, § 50-16-603, § 50-18-109, § 50-16-109

State	General Provisions	Exceptions to Use or Disclosure			Exceptionalism			MSHPA Provisions			MESHPA		CITATIONS
	Presumption of non-disclosure	De-identified for statistical analysis	Contact tracing/partner notification	Protect public health	HIV	STDs	Other conditions	Public record	Permits disclosure to federal authorities	Secondary disclosure	Suspect BT cases disclosed to law	Other disclosure to law enforcement	
	PRESNONDIS	EXRESEARCH	EXCONTRACE	EXPROPH	ISMHIV	ISMSTD	ISMOTH	MSHPAPUB	MSHPAFED	MSHPASECOND	MESHPABTLE	MESHPALIMLE	
NE	1	1	0	0	0	0	0	1	1	0	0	0	NE ST § 71-503.01, § 71-6737
NV	1	1	0	1	0	0	0	0	0	0	0	0	NV ST. § 441A.220, § 439.538.
NH	1	1	0	0	0	0	0	1	0	0	0	0	N.H. Rev. Stat. § 141-C:10; N.H. Code Admin. R. He-P 301.08
NJ	1	0	0	1	0	1	0	1	0	0	0	0	NJ ST 26:4-23, 26:4-41
NM	1	1	0	1	1	1	0	1	1	1	1	1	NM ST § 24-1-7, § 24-1-9.4, § 24-1-20
NY	0	0	0	0	1	0	0	1	0	0	0	0	N.Y. Public Health Law § 2135, § 2134; N.Y. Tax § 171-a & b
NC	1	0	0	1	0	0	0	1	1	1	0	0	NC ST § 130A-12, § 130A-15, § 132-1; ACT-UP Triangle v. Commission for Health Services of
ND	1	0	0	1	1	0	0	1	0	0	0	0	ND ST § 23-07-02.1, § 23-07-02.2, § 23-07-20.1, § 44-04-18
OH	1	1	0	1	1	0	0	1	0	0	0	0	OH ST § 3701.23, § 3701.243, 5112.21, § 149.43
OK	1	1	1	1	0	0	0	0	0	0	0	0	63 OK ST § 1-502.2
OR	1	1	1	1	0	0	0	1	0	1	0	0	OR ST § 433.008, § 242.722
PA	1	0	0	1	1	0	0	1	0	1	0	0	35 PA ST § 521.15, 35 PA ST § 7607, 65 PA ST 66.1
RI	0	0	0	0	0	0	0	1	0	0	0	0	RI ST § 38-2-2
SC	0	0	0	0	0	1	0	0	0	0	0	0	SC ST § 44-29-135, § 44-29-250
SD	1	1	0	1	1	1	0	0	0	0	0	0	SD ST § 34-23-2, § 34-22-12.1
TN	0	0	0	0	1	1	0	1	0	0	0	0	TN ST § 10-7-301(6), § 68-5-703, § 68-10-113
TX	1	1	0	1	0	0	0	0	1	1	0	0	TX Health & Safety Code § 81.046
UT	1	0	1	1	1	0	0	1	1	0	0	0	UT ST § 26-6-3.5, § 26-6-7, § 63-2-103
VT	0	0	0	0	1	1	0	1	0	0	0	0	18 V.S.A. § 1001; 18 V.S.A. § 1099; 1 V.S.A. 317
VA	0	0	0	0	1	0	0	1	0	0	0	0	VA ST § 32.1-36.1, § 32.1-36
WA	0	0	0	0	1	1	0	1	0	0	0	0	WA ST § 70.24.105, § 40.14.010
WV	0	0	0	0	1	1	0	1	0	0	0	0	WV ST § 16-4-6, § 16-3C-3, § 4-3-5©
WI	0	0	0	0	0	1	0	1	0	0	0	0	W.S.A. 252.11
WY	0	0	0	0	0	1	0	1	0	0	0	0	W.S. § 35-4-132
TOTAL	25	16	7	23	28	15	7	39	9	9	2	5	
* Distinguishes between infectious and non-infectious disease.													

REFERENCES

- ¹ Warren SD, Brandeis LD. The Right to Privacy. 4 Harvard Law Review 5 (1890).
- ² U.S. Const. amend. XIV.
- ³ Jacobson v. Commonwealth of Massachusetts, 197 U.S. 11 (1905).
- ⁴ Gostin L. Public health law: Power, duty, restraint. Berkeley (CA); University of California Press; 2000.
- ⁵ Neslund VS, Goodman RA, Hadler JL. Frontline public health: Surveillance field epidemiology. In: Goodman R, Hoffman RE, Lopez W, Matthews GW, Rothstein MA, Foster KL, editors. Law in public health practice. 2nd ed. New York: Oxford University Press; 2007. p. 222-237.
- ⁶ Avery G. Bioterrorism, Fear, and Public Health Reform: Matching a Policy Solution to the Wrong Window. Public Administration Review 2004; 64(3):275-288.
- ⁷ Friedman TL. The world is flat: a brief history of the 21st century. New York: Farrar, Straus and Giroux; 2005.
- ⁸ Centers for Disease Control and Prevention. National Biosurveillance Strategy: Predecision Working Paper (DRAFT). 2008 May 31.
- ⁹ Turnock B. Public health: what it is and how it works. 3rd ed. Sudbury (MA): Jones and Bartlett; 2004.
- ¹⁰ Institute of Medicine. The Future of the Public's Health in the 21st Century. Washington, DC: National Academy Press; 2002.
- ¹¹ U.S. Const. amend. X.
- ¹² Abercrombie TF. History of public health in Georgia 1733-1950. Atlanta: Georgia Department of Public Health; n.d. c 1950.
- ¹³ 42 U.S.C. § 241(a) (2008).
- ¹⁴ Gostin L, Hodge J. The public health law improvement process in Alaska: Toward a model public health law. 17 Alaska L. Rev 77, 2000.
- ¹⁵ Gostin L, Sapsin JW, Teret SP, Burris S, Mair JS, Hodge JG, Vernick JS. The Model State Emergency Health Powers Act: Planning for and Response to Bioterrorism and Naturally Occurring Infectious Diseases, 288 JAMA 622 (2002).
- ¹⁶ 42 U.S.C. § 247d-4 (2007).

¹⁷ Homeland Security Presidential Directive/HSPD-21 [news release]. Washington, DC: The White House; 18 Oct 2007 [cited 2008 Aug 1]. Available from: <http://www.whitehouse.gov/news/releases/2007/10/20071018-10.html>

¹⁸ 5 U.S.C. § 552a (2008).

¹⁹ Health Insurance Portability and Accountability Act of 1996. Pub. L. No. 104-191, 110 Stat. 1936 (1996).

²⁰ U.S. Const. amend XIV.

²¹ Hodge J, Gostin L, Vernick JS. The pandemic and all-hazards preparedness act. *Journal of the American Medical Association*. 2007 Apr. 18; 327(15):1708-1720.

²² Nagel S, Nagel R. *Encyclopedia of Policy Studies*. 2nd ed. New York (NY): Marcel Dekker; 1994.

²³ Fitzpatrick JL, Sanders JR, Worthen BR. *Program Evaluation: Alternative Approaches and Practical Guidelines*. Boston, MA: Pearson Education; 2004.

²⁴ Chriqui JF, O'Connor JC, Smith Eidson. Challenges and Opportunities in Measuring the Policy "Black Box: for Use in Public Health Evaluation Studies. Presented at the Joint 2005 CES/AEA Conference, Toronto, Canada, Oct 28, 2005.

²⁵ Sabatier PA, editor. *Theories of the policy process: theoretical lenses on public policy*. Colorado: Westview Press; 1999.

²⁶ World Health Organization. *International Health Regulations (2005)*. [cited 2008 Sept 1]. Available from: <http://www.who.int/csr/ihr/en/>.

²⁷ Baker MG, Fidler DP. Global public health surveillance under new international health regulations. *Emerging Infectious Diseases* 2006; 12(7):1058-1065.

²⁸ Centers for Disease Control and Prevention. *Public Health Surveillance Slide Set*. [Cited 2008 Sept 15]. Available from: <http://www.cdc.gov/ncphi/diss/nndss/phs/overview.htm>.

²⁹ Mariner WK. Mission creep: public health surveillance and medical privacy. 87 *Boston University Law Review* 347 (2007).

³⁰ Centers for Disease Control and Prevention. *Public Health Surveillance Slide Set*. [Cited 2008 Sept 15]. Available from: <http://www.cdc.gov/ncphi/diss/nndss/phs/overview.htm>.

³¹ Teutsch S., Churchill RE. *Principles and Practice of Public Health Surveillance*. New York: Oxford University Press; 2000.

-
- ³² Chorba TL, Berkelman RL, Safford SK, Gibbs NP, Hull HF. Mandatory reporting of infectious disease by clinicians. *Morbidity and Mortality Weekly Report*. 22 June 1990; 39(RR-9):19-23.
- ³³ Arita I, Nakane M, Kojima K, Yoshihara N, Nakano T, El-Gohary A. Role of a sentinel surveillance system in the context of global surveillance of infectious diseases. *The Lancet Infectious Diseases*. 4, 2004. 171- 177.
- ³⁴ Zhong N, Zeng G. What we have learnt from SARS epidemics in China. *British Medical Journal*, 2006 Aug 19;333(7564):389-91.
- ³⁵ Centers for Disease Control and Prevention. Guidelines for evaluating surveillance systems. *Morbidity and Mortality Weekly Report*. 998;37(S-5):8-10.
<http://www.cdc.gov/STD/Program/surveillance/4-PGsurveillance.htm>
- ³⁶ Stoto MA. Public health surveillance in the twenty-first century: achieving population health goals while protecting individuals' privacy and confidentiality. *96 Georgetown Law Journal* 703 (2008).
- ³⁷ Roush S, Birkhead G, Koo D, Cobb A, Fleming D. Mandatory Reporting of Diseases and Conditions by Health Care Professionals and Laboratories. *Journal of American Medical Association*. 14 Jul 1999; 281(2): 164-170.
- ³⁸ Ransom MM, Goodman RA, Moulton AD. Addressing gaps in health care sector legal preparedness for public health emergencies. *Disaster Medicine and Public Health Preparedness*. 2008; 2:50-56.
- ³⁹ Chorba TL, Berkelman RL, Safford SK, Gibbs NP, Hull HF. Mandatory reporting of infectious disease by clinicians. *Morbidity and Mortality Weekly Report*. 22 June 1990; 39(RR-9):19-23.
- ⁴⁰ Jajosky RA, Groseclose SL. Evaluation of reporting timeliness of public health surveillance systems for infectious diseases. *BMC Public Health*, 2004 Jul 26; 4:29.
- ⁴¹ Goodman RA, Buehler JW, Koplan JP. The epidemiologic field investigation: science and judgment in public health practice. *American Journal of Epidemiology* 1990; 132:9-16.
- ⁴² Gregg MB. Conducting a field investigation. In: Gregg MB, ed. *Field Epidemiology*. New York: Oxford University Press, 2001: 62-77.
- ⁴³ U.S. Const. amend. X.
- ⁴⁴ U.S. Const. art. 1, sec. 8.
- ⁴⁵ 42 U.S.C. 301(a) (2008).

⁴⁶ 42 U.S.C. 241(a) (2008).

⁴⁷ 42 U.S.C. 247d (2008).

⁴⁸ Broome CV, Horton HH, Tress D, Lucido SJ, Koo D. Statutory basis for public health reporting beyond specific diseases. *Journal of Urban Health*. 2003 Jun; 80(2 Suppl 1):114-22.

⁴⁹ Council of State and Territorial Epidemiologists [homepage on the internet]. Atlanta, GA: CSTE [cited 2008 Sept 24]. Available from: <http://www.cste.org/dnn/AboutCSTE/tabid/55/Default.aspx>.

⁵⁰ Horton H, Misrahi JJ, Matthews GW, Kocher PL. Critical biological agents: disease reporting as a tool for bioterrorism preparedness. *Journal of Law, Medicine, and Ethics* 2002; 30:262-66.

⁵¹ Chorba TL, Berkelman RL, Safford SK, Gibbs NP, Hull HF. Mandatory reporting of infectious disease by clinicians. *Morbidity and Mortality Weekly Report*. 22 June 1990; 39(RR-9):19-23.

⁵² Goldman J. Balancing in a crisis? Bioterrorism, public health and privacy. 38 *Journal of Health Law* 481 (2005).

⁵³ Bryan RT, Pinner RW, Berkelman RL. Emerging infectious diseases in the United States, Improved surveillance, a prerequisite for prevention. *Ann NY Acad. Sci.* 1994 Dec 15; 740:346-61.

⁵⁴ Khan A, Deputy Director of the National Center for Zoonotic, Vector-borne, and Enteric Diseases, pers. comm.

⁵⁵ Hodge JG Jr, Brown EF, O'Connell JP. The HIPAA privacy rule and bioterrorism planning, prevention, and response. *Biosecurity and Bioterrorism*. 2004; 2(2):73-80.

⁵⁶ CDC and DOJ Public Health and Law Enforcement Emergency Preparedness Workgroup. Joint Public Health-Law Enforcement Investigations: Model Memorandum of Understanding (MOU). [Draft received by personal communication from Richard Goodman].

⁵⁷ Gostin LO. Health information: reconciling personal privacy with the public good of human health. *Health Care Analysis*. 2001; 9: 321-335.

⁵⁸ Magnusson RS. The changing legal and conceptual shape of health care privacy. *Journal of Law, Medicine and Ethics*. 2004 Winter; 32(4):680-91.

⁵⁹ CDC-CSTE Intergovernmental Data Release Guidelines Working Group. CDC-ATSDR data release guidelines and procedures for re-release of state provided data. Atlanta (GA):

Council of State and Territorial Epidemiologists; 24 Jan 2005 [cited 21 Set 2008]. Available from: <http://www.cdc.gov/od/foia/policies/drgwg.pdf>.

⁶⁰ Stone, D. *Policy paradox: The art of political decision making*. 2nd ed. New York (NY): W.W. Norton & Co.; 2002.

⁶¹ Mill JS. *On Liberty*. 2nd ed. Boston: Ticknor and Fields; 1863.

⁶² Shenk D. Surveillance society: Openness is the best defense against intrusions into our private realms. *European Molecular Biology Organization Reports*. 2006 Jul; 7 Spec No:S31-5.

⁶³ Starr P. Health and the right to privacy. 25 *American Journal of Law and Medicine* 193 (1999).

⁶⁴ Magnusson RS. The changing legal and conceptual shape of health care privacy. *Journal of Law, Medicine and Ethics*. 2004 Winter; 32(4):680-91.

⁶⁵ Hodge JG. Health information privacy and public health. 31 *Journal of Law, Medicine, and Ethics* 663 (2003).

⁶⁶ Gostin LO, Hodge JG. Personal privacy and common goods: a framework for balancing under the national health information privacy rule. 86 *Minnesota Law Review* 1439 (2002).

⁶⁷ Gostin LO. The Public Health Information Infrastructure. *A National Review of the Law on Health Information Privacy*, 275 *JAMA* 1921 (1996).

⁶⁸ Mariner WK. Mission creep: public health surveillance and medical privacy. 87 *Boston University Law Review* 347 (2007).

⁶⁹ Cassa CA, Grannis SJ, Overhage JM, Mandl KD. A context-sensitive approach to anonymizing spatial surveillance data: impact on outbreak detection. *Journal of the American Medical Informatics Association*. 2006 Mar-Apr; 13(2):160-5.

⁷⁰ Olson KL, Grannis SJ, Mandl KD. Privacy protection versus cluster detection in spatial epidemiology. *American Journal of Public Health*. 2006 May; 96(11):2002-8.

⁷¹ Gostin LO. "Police" powers and public health paternalism: HIV and diabetes surveillance. *Hastings Center Report*. 2007 Mar-Apr; 37(2):9-10.

⁷² Hardin G. The Tragedy of the Commons. *Science*. 1968; 162 (3859):1243-1248.

⁷³ Bayer R, Fairchild A. The limits of privacy: surveillance and the control of disease. *Health Care Analysis*. 2002; 10(1):19-35.

-
- ⁷⁴ Bayer R, Fairchild AL. Public health. Surveillance and privacy. *Science*. 2000 Dec 8; 290(5498):1898-9. Erratum in: *Science* 2000 Dec 15; 290(5499):2075b.
- ⁷⁵ Fairchild AL, Gable L, Gostin LO, Bayer R, Sweeney P, Janssen RS. Public goods, private data: HIV and the history, ethics and uses of identifiable public health information. *Public Health Reports*. 2007; 122 (Suppl 1):7-15.
- ⁷⁶ Goldman J. Balancing in a crisis? Bioterrorism, public health and privacy. 38 *Journal of Health Law* 481 (2005).
- ⁷⁷ The Pandemic and All Hazards Preparedness Act of 2006, Pub. L. No. 109-417
- ⁷⁸ Homeland Security Presidential Directive/HSPD-10: Biodefense for the 21st Century [news release]. Washington, DC: The White House; 2004 Apr 28 [cited 2008 Sept 1]. Available from: <http://www.fas.org/irp/offdocs/nspd/hspd-10.html>
- ⁷⁹ Roos R. Proposed Homeland Security Department would take over bioterrorism-related work [news release]. University of Minnesota: Center for Infectious Disease Research and Policy; 2002 Jun 7 [cited 2009 Aug 1]. Available from: <http://www.cidrap.umn.edu/cidrap/content/bt/bioprep/news/homeland.html>
- ⁸⁰ The National Commission on Terrorist Attacks Upon the United States. The 9-11 Commission Report. Washington, DC; 22 July 2004 [cited 2008 Aug 1]. Available from <http://www.gpoaccess.gov/911/Index.html>
- ⁸¹ Baker MG, Fidler DP. Global public health surveillance under new international health regulations. *Emerging Infectious Diseases* 2006; 12(7):1058-1065.
- ⁸² World Health Assembly. Revision of the international health regulations, WHA58.3. 2005 [cited 2008 May 1]. Available from http://www.who.int/gb/ebwha/pdf_files/WHA58-REC1/english/Resolutions.pdf.
- ⁸³ U.S. Const. amend V.
- ⁸⁴ U.S. Const. amend XIV.
- ⁸⁵ *Planned Parenthood of Central Missouri v. Danforth*, 428 U.S. 52 (1976).
- ⁸⁶ *Whalen v. Roe* 429 U.S. 589 (1977).
- ⁸⁷ *Tucson Woman's Clinic v. Eden*, 279 F.3d 531 (9th Cir. 2004).
- ⁸⁸ 5 U.S.C. §552 (2008).
- ⁸⁹ 5 U.S.C. § 552a (2008).

⁹⁰ 45 C.F.R Part 46 (2008).

⁹¹ 44 U.S.C. § 3601 (2008).

⁹² 20 U.S.C. §1232g (2008).

⁹³ Centers for Disease Control and Prevention. CDC/ATSDR Policy on Releasing and Sharing Data (2005) [cited 15 Sept 2008]. Available from: <http://www.cdc.gov/od/foia/policies/sharing.htm#iii> .

⁹⁴ 42 U.S.C. § 290dd-2 (2008).

⁹⁵ Centers for Disease Control and Prevention. CDC/ATSDR Policy on Releasing and Sharing Data (2005) [cited 15 Sept 2008]. Available from: <http://www.cdc.gov/od/foia/policies/sharing.htm#iii> .

⁹⁶ Hodge JG Jr, Brown EF, O’Connell JP. The HIPAA privacy rule and bioterrorism planning, prevention, and response. *Biosecurity and Bioterrorism*. 2004; 2(2):73-80.

⁹⁷ 45 C.F.R. § 160.202.

⁹⁸ Drociuk D, Gibson J, Hodge J Jr. Health information privacy and syndromic surveillance systems. *Morbidity and Mortality Weekly Report*. 2004 Sep 24; 53 (Suppl):221-5.

⁹⁹ Ziskin LZ, Harris DA. State health policy for terrorism preparedness. *American Journal of Public Health*. 2007 Sep; 97(9):1583-8.

¹⁰⁰ *Jacobson v. Commonwealth of Massachusetts*, 197 U.S. 11 (1905).

¹⁰¹ Hodge JG. Health information privacy and public health. *31 Journal of Law, Medicine, and Ethics* 663 (2003).

¹⁰² Gostin LO. Public health law reform. *American Journal of Public Health*. 2001; 91(9):1365.

¹⁰³ Gostin LO. Informational Privacy and the Public’s Health” *The Model State Public Health Privacy Act* 91 *Am. J. Pub Health* 1388 (2001).

¹⁰⁴ Public Health Statute Modernization Excellence Collaborative. *Model State Public Health Act: A Tool for Assessing Public Health Laws*. Turning Point National Program Office, University of Washington. n.d. [cited 2008 Aug 1]. Available from: http://www.turningpointprogram.org/Pages/ph_stat_mod.html.

¹⁰⁵ Gostin, Lawrence, Hodge James. *The Model State Emergency Health Powers Act – Brief Commentary*. Seattle, WA: Turning Point National Program Office at the University of

Washington, September 2002 [cited 2008 Sept 24]. Available from: http://www.turningpointprogram.org/Pages/pdfs/statute_mod/phsm_model_emergency_law_full.pdf.

¹⁰⁶ Reich D. Modernizing local responses to public health emergencies: Bioterrorism, epidemics, and the Model State Emergency Health Powers Act. 19 J. Contemp. Health L& Policy 379 (2003))

¹⁰⁷ Ziskin LZ, Harris DA. State health policy for terrorism preparedness. American Journal of Public Health. 2007 Sep; 97(9):1583-8.

¹⁰⁸ Moulton AD, Gottfried RB, Goodman RA, Murphy AM, and Rawson RD, What is public health legal preparedness? Journal of Law, Medicine, and Ethics, 31 (2003) 1-12.

¹⁰⁹ Matthews GW, Benjamin G, Mills SP, Parmet W, Misrahi JJ. Journal of Law, Medicine, and Ethics. 2002 Fall; 30(3 Suppl.):52-6.

¹¹⁰ Martin R. Law as a tool in promoting and protecting public health: always in our best interests? Public Health 2007; 121: 846-853.

¹¹¹ CDC. Continuation Guidance—Budget Year 5. Attachment B. Focus B: Surveillance and epidemiology capacity. 14 June 2004:1-8.

¹¹² Public health preparedness: response capacity improving, but much remains to be accomplished. GAO Testimony Statement of Janet Heinrich before the Committee on Government Reform, House of Representatives, 108th Cong. 2004 Feb 12 [cited 29 Aug 2008]. Available from: <http://www.gao.gov/new.items/d04458t.pdf>.

¹¹³ Statement for the record by the Government of the United States of America concerning the World Health organization's revised International Health Regulations. 2005 May 23 [cited 15 Sept 2008].

¹¹⁴ Fidler DP. Globalization, international law, and emerging infectious diseases. Emerging Infectious Diseases. April 1996 Apr; 2(2).

¹¹⁵ Creswell JW. Qualitative Inquiry and Research Design: Choosing Among the Five Traditions. California: Sage Publications; 1998.

¹¹⁶ Westlaw.com [database on the Internet] c2007 [cited 1 Aug 2008]. Available from: www.westlaw.com.

¹¹⁷ Nagel S, Nagel R. Encyclopedia of Policy Studies. 2nd ed. New York (NY): Marcel Dekker; 1994.

¹¹⁸ National Institutes of Health. National Cancer Institute. ASSIST: Shaping the Future of Tobacco Prevention and Control. Smoking and Tobacco Control Monograph No. 16. NIH Pub. No. 05-5645, May 2005.

¹¹⁹ Centers for Disease Control and Prevention. State Tobacco Activities Tracking and Evaluation (STATE) System [cited 2008 Jul 31]. Available from: <http://www.cdc.gov/tobacco/statesystem>.

¹²⁰ ImpacTeen [homepage on the Internet]. Chicago: University of Illinois at Chicago; Institute for Health Research and Policy [cited 2008 Jul 31]. Available from: <http://impacteen.econ.uic.edu>.

¹²¹ LaFond C, Toomey TL, Rothstein C, Manning W, Wagenaar A. Policy Evaluation Research: Measuring the Independent Variables. *Evaluation Review*. 2000 Feb; 24(1): 92-101.

¹²² Kunz CL, Downs MP, Schmedemann D, Bateson AL. *Process of Legal Research*. Aspen: United States, 2004.

¹²³ O'Connor JC, Chriqui J, McBride D. Finding Lasting Legal Solutions to the Dual Epidemics of Methamphetamine Production and Use. *82 North Dakota Law Review* 1165, 2006.

¹²⁴ ImpacTeen Illicit Drug Team. *Illicit drug policies: Selected laws from the 50 states*. Berrien Springs (MI): Andrews University; 2002 [cited 1 Aug 2008]. Available from: www.rwjf.org/files/publications/other/DrugPoliciesReport.pdf.

¹²⁵ Sosin D. Interagency disease information sharing: Federal HSPD-21 biosurveillance workgroup. Oral Presentation at the National Science Foundation Interagency Disease Sharing Meeting. Arlington, Virginia. 2008 Feb 14.

¹²⁶ State Health Leadership Initiative [homepage on the Internet]. [cited 2008 Aug 1.] Available from: http://www.statepublichealth.org/index.php?template=landing.php§ion=shli_login

¹²⁷ CNN Election Center [webpage on the Internet] [cited Aug 1, 2009]. Available from: <http://www.cnn.com/ELECTION/2008/results/president/>

¹²⁸ Krippendorff K. *Content Analysis: An Introduction to Its Methodology*, Sage Publishers: New York, 2003.

¹²⁹ Atlas.ti [homepage on the Internet]. Berlin: ATLAS.ti Scientific Software Development; c2008 [cited 1 Aug 2008]. Available from: <http://www.atlasti.com/applications.html>.

¹³⁰ Young TK. *Population Health: Concepts and Methods*. 2nd ed. New York: Oxford; 2005.

¹³¹ U.S. Const. amend IV.

¹³² Gostin LO. Public health law reform. *American Journal of Public Health*. 2001; 91(9):1365.

¹³³ KY ST § 214.181 (2008).

¹³⁴ C.G.S.A. § 19a-262 (2008).

¹³⁵ SD ST § 34-23-2 (2008).

¹³⁶ TN ST § 68-10-113 (2008).

¹³⁷ N.J.S.A. § 26:4-41 (2008).

¹³⁸ ND ST §23-07-02.2 (2008).

¹³⁹ R.C.W.A. 0.02.050 (2008).

¹⁴⁰ A.R.S. § 36-664 (B) (2008).

¹⁴¹ C.G.S.A. § 17b-225 (2008).

¹⁴² KS ST § 65-102b (2008).

¹⁴³ MT ST § 50-16-603 (2008).

¹⁴⁴ Gould T. *A Summer Plague: Polio and its Survivors*. New Haven, CT: Yale University Press; 1995.

¹⁴⁵ White House Issues—Health Care [page on the Internet] [cited June 2, 2009]. Available from: http://www.whitehouse.gov/issues/health_care/.

¹⁴⁶ Remarks of President Barack Obama. Weekly Address. Saturday May 2, 2009 [cited June 2, 2009]. Available from: http://www.whitehouse.gov/the_press_office/WEEKLY-ADDRESS-President-Obama-Outlines-Government-Actions-to-Address-the-2009-H1N1-Flu/.

¹⁴⁷ White House Issues—Homeland Security and Counter Terrorism [page on the Internet] [cited June 2, 2009]. Available from: http://www.whitehouse.gov/issues/homeland_security/.

¹⁴⁸ Information Sharing Environment [homepage on the Internet] [cited Jun 2, 2009]. Available from: <http://www.ise.gov/pages/vision.html>.

¹⁴⁹ Gilpin E. State Facilitating Barriers and Conditions to Implementation of Tobacco Control Programs. In Stillman F (ed). Monograph 17: Evaluating ASSIST, A blueprint for understanding state-level tobacco control. Washington, DC: National Cancer Institute; 2005.

¹⁵⁰ Shapiro H, Meslin EM. Relating to History: The Influence of the National Commission and its Belmont Report on the National Bioethics Advisory Commission. In Childress JF, Meslin EM, Shapiro H (eds). Belmont Revisited. Georgetown University Press: Washington, DC, 2005.

¹⁵¹ Public Health Leadership Society. Principles of the Ethical Practice of Public Health. Washington, DC; APHA; 2002.

¹⁵² Kotter J. Leading change. Boston, MA: Harvard Business School Press; 1996.

¹⁵³ Collins J. Good to great and the social sectors. San Francisco, CA: Elements Design Group; 2005.