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DIFFERENCES IN DISEASE REPORTING: AN ANALYSIS OF STATE REPORTABLE CONDITIONS AND THEIR RELATIONSHIP TO THE NATIONALLY NOTIFIABLE CONDITIONS LIST

By

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Abstract

The basis of public health surveillance is the reporting of diseases and conditions to the health department by clinicians and laboratories. In the United States, over eighty diseases and conditions of national importance (e.g., tuberculosis, syphilis, and cancer) are included on the list of Nationally Notifiable Conditions (NNC) for submission to the Centers for Disease Control and Prevention (CDC) by the states. The legal basis for disease reporting is found at the state level, where inconsistent laws may differ in terms of which conditions are reportable and their reporting process. The process by which states require the reporting of NNCs has not been thoroughly described, and the potential bias introduced by different reporting requirements has not been evaluated.

State reportable disease lists were collected from state health department websites, state laws, and published CDC annual summaries. A descriptive, cross-sectional analysis of the reporting requirements of all 50 states, Washington D.C. and New York City was conducted. Factors associated with the states (e.g., population, public health funding) were evaluated to determine if any were associated with having large number of NNCs on the state's reportable lists. Factors associated with the conditions (e.g. being vaccine preventable or a bioterrorism agent) were evaluated to determine if any were associated with the inclusion on state reporting lists. Additionally, pediatric influenza mortality, lead poisoning, tuberculosis and Shiga toxinproducing Escherichia coli infections were selected for an in-depth analysis of state reporting requirements.

States required 76% to 100% (mean 90%) of NNCs to be reported; only Louisiana required the reporting of all NNCs. No factors associated with the conditions were identified as having a significant association with being included on state reportable lists; only 43% of NNCs

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were reportable in all states. States used 28 different reporting timeframes and required reporting by 72 different types of reporters. Having a larger state population was associated with requiring a greater number of NNCs to be reported, but no linear relationship was identified. Detailed analysis of the selected conditions found that states did not follow national recommendations when setting state reporting criteria; the inclusion of a new condition on the NNC list is a reflection of reporting practices already established in states, and as such, is not an effective tool to change state reporting practices.

NNC data is frequently used in policy making, funding, and program evaluation, and bias introduced by different state reporting practices may make data collected unreliable for these purposes. This study proposes a method for the standardization of reporting practices across states, allowing for the standardize collection and interpretation of NNC data.

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Dedication

This is dedicated to the memory of my grandmother, Susan Bonko. She was always my biggest supporter, and I wish she could be here with me at the end of this long road.

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Chapter 1 – Introduction

Introduction

In December of 2014, the Centers for Disease Control and Prevention (CDC) released the 2013 annual summary data for sexually transmitted infections. The news media focused on interstate differences in this report, leading stories with "Obviously you shouldn't have unprotected casual sex, but it you do, you might want to avoid the Deep South" (Moffitt, 2015). The report states in the appendix that "...differences in policies and systems for collecting surveillance data may exist. Thus, comparisons of case numbers and rates between jurisdictions should be interpreted with caution." (Centers for Disease Control and Prevention, 2014f, p. 128) However, this admonition was obviously ignored by the media, where national data are typically treated as if bias during the data collection process does not exist or does not affect the collected data.

Journalists are not the only people who fall into the trap of ignoring the limitations of data. Scientific researchers using the Nationally Notifiable Diseases Surveillance System (NNDSS) often fail to consider the role of interstate differences in the disease reporting process, the effects of which may be magnified when evaluating small populations or rare diseases. For example, in an evaluation of racial and ethnic differences in disease reporting of 26 conditions from 2007-2011, Adekoya, Truman and Landen (2015) found that fewer than 1% of case reports made in NNDSS were for American Indians/Alaska Natives, with five of these conditions having an average of fewer than ten reports per year. Underlying legal differences in disease reporting differences in disease reporting differences of the over- or under- reporting of a single case being potentially statistically significant.

The legal basis for the NNDSS, an integrated system of state-based surveillance systems that provides a national picture of disease in the United States, is rooted in a variety of state laws and codes. Issues of bias related to the underlying legal process of collecting data are rarely understood, much less considered, when the data are ultimately utilized as part of policy or research decisions.

In general, the process by which conditions are added to the Nationally Notifiable Conditions (NNC) list and placed under national surveillance within the NNDSS, a core piece of the data collection system for basic public health surveillance in the United States, is not well described, and the bias introduced into the system by having different reporting criteria in each state has not been thoroughly described or evaluated.

Statement of the Problem

A gap in the literature was identified concerning the process of annually updating the list of nationally notifiable conditions. When a disease is added to the list, it is officially recommended that "all States and Territories enact laws (statue or rule/regulation as appropriate) to make this disease or condition reportable in their jurisdiction." (Council of State and Territorial Epidemiologists, 2015, p. 2) Additionally, the formal recommendation to add a condition to the nationally notifiable conditions list (as well as subsequent updates) contains guidance on how public health jurisdictions should implement the disease reporting requirements in terms of 1) who should be required to make the report and 2) the clinical criteria that should instantiate a report and 3) laboratory criteria that should instantiate a report.

To date, there has been no systematic evaluation of how states implement reporting requirements within their disease reporting legal framework. Additionally, there has been no evaluation of the states' implementation of specific reporting criteria, and it is currently unknown

if what is reportable in the states matches the agreed-upon national recommendations. As a result, it is not possible to compare data across states with any level of confidence.

Background

The World Health Organization (2015) defines public health surveillance as the "continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice" (para. 1), which recognizes the sustained effort required to conduct surveillance, its scientific basis, and its applied nature. Sullivan et. al (2010) describe public health surveillance more simply as "information for action." (p. 88). In short, public health surveillance provides the data needed to drive public health action and to evaluate the results of those actions.

In the United States, the foundation of national-level disease surveillance is the Nationally Notifiable Diseases Surveillance System (NNDSS). The NNDSS is a collaborative system across all government health departments (from local through federal) and including numerous surveillance systems to collect and share data for the understanding, prevention and control of disease in the United States (Centers for Disease Control and Prevention, 2014b). The NNDSS has evolved out of a need for state and local government to take action in response to public health threats at the individual level. For example, the reporting of an individual case of disease may result in isolation of the ill person and prophylaxis of the ill person's direct contacts.

At the population level, information about the individual cases can be aggregated to paint a community picture of disease that allows the citizens to understand the patterns and severity of morbidity in the population. The data collected by the system are not collected to identify new risk factors, but rather to describe how established risk factors are changing over time. Additionally, the data can be used to generate hypotheses for additional studies; however, they

do not contain a comparison group and cannot be used directly for hypothesis testing. As a result, the NNDSS is designed to collect data that are analyzed using cross-sectional, descriptive methods. The ongoing nature of data collection of NNDSS data allows for descriptive analysis of the temporal aspect of the data, which can be used to describe changes in morbidity patterns over time.

The NNDSS has a number of purposes related to national surveillance of disease, which are described by the Centers for Disease Control and Prevention (2014b) as to:

- collect, manage, share, analyze, interpret, and disseminate health-related data for statereportable and nationally notifiable diseases and conditions;
- develop and maintain national standards—such as consistent case definitions and electronic messaging standards;
- monitor regional and national trends in diseases and health conditions;
- work with other jurisdictions and partners to implement and assess prevention and control programs;
- designate certain diseases and conditions as nationally notifiable;
- submit data on nationally notifiable diseases to CDC; and
- maintain and publish the official national notifiable diseases statistics from 57 state, territorial, and local reporting jurisdictions in the *Morbidity and Mortality Weekly Report*

(p. 1)

While the general operation of NNDSS is managed by the CDC, the system is based on the United States' federated legal model of public health. Congress is limited to the powers specifically proscribed in the Constitution, leaving the general responsibility for public health to the individual states and territories (Velikina, Dato, & Wagner, 2006). While the legal authority for surveillance rests at the state and local level, communicable diseases do not respect such artificial divisions, and it is necessary for public health authorities to work together across jurisdictional and state lines and at the national level to protect citizens from disease. The United States system of disease surveillance evolved to standardize many aspects of the process while allowing state and local health departments to retain their autonomy, providing the flexibility to tailor the system to local needs. As a result, national disease surveillance in the United States is not a single nationwide system, but rather a set of interconnected state systems with a decentralized management structure and no legal requirement that states actually participate. It is best described as being a "system of systems" rather than a single system (Adams, et al., 2014).

The tenth amendment of the United States Constitution reserves public health police powers for the states (Hodge Jr., 1998). As a result, the legal authority to mandate the reporting of conditions to the health authority rests with the individual state legislatures and is implemented through a variety of legal means (Chorba, Berkelman, Safford, Gibbs, & Hull, 1989). Local health departments have occasionally mandated the reporting of additional diseases at the city or county level based on the legal authority provided to the local health department in a given state, although this process is not widespread in the United States (Allegheny County Health Department, 2002; County of Los Angeles Department of Public Health, 2012; Colorado Department of Public Health and Environment, 2005; Nevada Division of Public and Behavioral Health, 2007).

There are 57 public health jurisdictions in the United States that voluntarily notify CDC directly of nationally notifiable conditions (Centers for Disease Control and Prevention, 2014b) through the NNDSS and would be considered "state-level" health departments. These include the 50 states, the five US territories (Guam, Puerto Rico, the US Virgin Islands, American Samoa

and the Commonwealth of Northern Mariana Islands), Washington DC, and New York City. There are approximately 2,800 public health jurisdictions in the United States that are considered to be "local" health departments that are organized under one of the state-level public health jurisdictions and do not notify CDC directly of nationally notifiable conditions (National Association of County and City Health Officials, 2014).

Individual states and territories are represented by the Council of State and Territorial Epidemiologists (CSTE), which has been charged with the maintenance of the list of nationally notifiable conditions since 1951. This includes modifying the list through adding and removing conditions, developing the case definitions to be used in national notification and establishing reporting criteria to be used at the state, territorial and local levels (Neslund, Goodman, Hadler & Hodge Jr., 2008). Conditions are added to the NNC by a majority vote of states at the CSTE Annual Conference, which is held in June. The additions, deletions and changes are then forwarded to the CDC for inclusion on the NNC list for the following calendar year. Any changes to the list are active as of the first day of Morbidity and Mortality Weekly Report (MMWR) week 1 of the reporting year, which is the first week of the year (starting on Sunday) that has four or more days in the calendar year (Centers for Disease Control and Prevention, n.d.).

As recently as 1990, the inclusion of a disease on the list of nationally notifiable conditions did not require the development of a standardized case definition for notification purposes. In a 1990 publication, CDC and CSTE jointly established a set of uniform surveillance case definitions for case notification, stating that "Surveillance demands uniformity, simplicity, and brevity" (Wharton, Chorba, Vogt, Morse, & Buehler). They also cautioned that these case

definitions were not sufficient to be used for patient care activities or "initiating public health actions".

Once a disease is added to or removed from the list of nationally notifiable conditions, it is up to individual states to determine if they will add or remove the condition from the list of reportable diseases within their jurisdiction and if so, determine the criteria by which the disease will be made reportable. This includes the entities required to report, the criteria used to trigger a report and the process by which the reported will be filed with the public health authority. These all must occur within the constraints of the state's established legal framework for disease reporting. While this process allows states to tailor their disease reporting regulations to match the needs of the population, it may introduce bias into a system that relies on consistency to allow for the comparability of data across jurisdictions (Sacks, 1985).

Significance of the Study

The NNDSS serves as the primary data source for numerous studies on the incidence, prevalence and risk factors for nationally notifiable conditions. Recent example of the uses of NNDSS data include studies of the descriptive epidemiology of Hansen's Disease (leprosy) in the United States over a 15-year period (Nolen, et al., Incidence of Hansen's Disease — United States, 1994–2011, 2014), a description of increasing incidence in primary and secondary syphilis, especially in men who have sex with men (Patton M. E., Su, Nelson, & Weinstock, 2014), and an estimation of the number of actual acute hepatitis cases based on reported cases (Klevens, Liu, Roberts, Jiles, & Holmberg, 2014). NNDSS data were also used widely as performance metrics for the CDC in Director Dr. Thomas Frieden's Congressional justification of CDC's Fiscal Year 2015 budget, including the number of incident cases of HIV, hepatitis A and hepatitis B, and the incidence rates of gonorrhea, syphilis and tuberculosis, Escherichia coli

O157:H7 infection, listeriosis and salmonellosis (Centers for Disease Control and Prevention, 2014a).

General guidelines on the use of NNDSS data state that "Surveillance practices, policies, priorities, and resources vary from state to state. Therefore, one should use caution when making state-to-state comparisons of disease incidence" (Centers for Disease Control and Prevention, 2001). Additionally, the NNDSS guidance cautions about temporal changes in the data collection process, as state resources and public health priorities may shift, possibly resulting in an inconsistent approach to surveillance for a given disease over time. In general, studies that use NNDSS data typically are concerned about bias in the process of data collection, but this focuses on incomplete disease reporting by clinicians and does not consider state-based reporting differences when discussing limitations.

Purpose of the Study

The purpose of this study is to better understand the implementation of the disease reporting and notification process at the state/territorial level in the United States, and to identify areas for potential improvement. Differences in the implementation of the process by states may result in problems with the validity of interstate comparisons of disease, and the degree to which this is an issue has not been described.

The first goal of the study is to understand how states and territories individually implement the reporting of nationally notifiable conditions and the factors that affect this implementation. For this goal, the 2015 reportable disease lists for each state-level reporting jurisdiction in the United States will be compared to the 2015 list of nationally notifiable conditions. The comparisons will answer two broad questions:

- 1. To what degree do all state-level public health jurisdictions require the reporting of conditions on the 2015 nationally notifiable conditions list?
- 2. What factors, if any, predict state-level public health jurisdictions' compliance with including 2015 nationally notifiable conditions on the state reportable conditions list?

The second goal of this study is to understand how quickly state reportable conditions lists are updated after a disease is added to the list of nationally notifiable conditions. For this goal, the implementation timeline for state public health jurisdictions to include a nationally notifiable condition on the list of state reportable diseases will be evaluated for a subset of diseases that were added to the nationally notifiable conditions list from 1992-2012.

The third goal of this study is to evaluate the states implementation of disease reporting requirements set forth in the CSTE position statement establishing a condition as nationally notifiable. For this goal, the state reporting requirements from all state-level public health jurisdictions for a subset of all notifiable conditions will be compared to the reporting recommendations made in the formal process of adding a disease to the nationally notifiable conditions list.

Key Terms

For the context of this study, definitions of relevant terms are provided below.

<u>Case</u> – A person who meets the clinical, laboratory, and epidemiologic criteria established as part of a confirmed or probable case definition for a condition.

<u>Condition</u> – a state of health in a person.

<u>Disease</u> – a condition of the body or mind that impairs normal functioning.

<u>Local health department</u> – a unit of local or state government responsible for the oversight of public health in a geographic area smaller than a state.

<u>Nationally Notifiable condition</u> – a condition for which information about cases should be transmitted to the CDC.

<u>Notification</u> – The process of a local or state public health authority submitting case information to CDC of a condition on the Nationally Notifiable Condition list (Council of State and Territorial Epidemiologists, 2015).

<u>Public health jurisdiction</u> – the state, county, city or regional governmental entity given legal authority over public health matters in a geographic area.

<u>Reportable condition</u> – a condition that, when identified by a clinician, laboratory or other entity designated by state law, must be reported to the public health jurisdiction as specified by the state.

<u>Reporting</u> – The process of a healthcare provider, laboratory or other entity submitting a case information to local or state public health of a condition under public health surveillance in the jurisdiction (Council of State and Territorial Epidemiologists, 2015).

<u>Reporting criteria</u> – clinical, laboratory or epidemiologic findings which require a clinician, laboratory or other designated entity to inform the state of the findings.

<u>State-level public health jurisdiction</u> – A public health entity responsible for notifying CDC of nationally notifiable conditions through the NNDSS. For this project, these entities include the 50 states, Washington DC, and New York City.

Summary

The NNDSS is the basis for morbidity surveillance in the United States and plays a key role in scientific and public health policy decisions. While the system is generally organized through the CDC at the national level, the constitutional underpinnings of public health place the legal authority for public health reporting at the state and local level. Given this legal framework,

NNDSS has evolved as a "system of systems" rather than a single, fully-integrated system. Biases introduced into the disease reporting process have not been well described in the literature, and as a result, concerns about the role of these biases are largely absent from scientific and policy considerations.

Chapter 2 – Review of Literature

"Good surveillance does not necessarily ensure the making of the right decisions, but it reduces the chance of wrong ones."

Alexander D. Langmuir, 1963

Introduction

When outbreaks of international concern occur, sensationalistic stories in popular media usually remind the public that it doesn't take long for disease to spread from a foreign part of the world to their hometown. From reasonable headlines such as "Ebola: The world of global infectious disease is getting smaller" (Samadi, 2014) to extreme headlines such as "You are not nearly scared enough about Ebola" (Garrett, 2014), the public is reminded of the potential local impact of diseases of international concern. While the media is often criticized that there is "always money to be made in fear mongering" (Horgan, 2014), it is not inappropriate to consider the local response to an outbreak if it were to spread locally.

The well-worn public health cliché that "all public health is local" is rooted in the idea that, first and foremost, the citizens need to protect themselves. As public health systems evolved in the United States, they were built around health departments at the state and local level, and not the national level. The oldest health department in the United States is a local health department and was founded in Boston in 1799 (Boston Public Health Commission, 2015). The Centers for Disease Control and Prevention, the agency responsible for public health at the national level, was not established until 1946 (Shaw, Goodman, Lindegren, & Ward, 2011).

Many of the challenges faced by disease surveillance systems today are a result of the historical evolution of disease surveillance in the United States and its roots in the need for local and state health departments to understand and respond to disease at the local level.

The Historical Foundations of Disease Reporting

The systematic, population-based collection of disease statistics can be traced to a need for governmental officials to understand the severity and spread of disease within their cities. In 1532, advisors to the King Henry VIII "commanded the mayor [of London] to certify how many have died of the plague" (Creighton, 1891, p. 294). From this requirement, the Bills of Mortality were first created, and provided weekly totals of deaths, separating out those from the plague, for the parishes of London (Moriyama, Loy, Robb-Smith, Rosenberg, & Hoyert, 2011).

The Bills of Mortality were sporadically published during plague outbreaks throughout the 16th century; they became consistently published on a weekly basis in 1611 by the Worshipful Company of Parish Clerks (Slauter, 2011). The weekly reports listed the number of deaths by cause, the parish in which the burial occurred, and the number of weekly christenings (Parish Clerks of London, 1665). These weekly reports were far from complete, as they provided no information on the decedent's age and completely excluded those buried outside the church, but they provided a basic insight into the health problems facing the people of London. Nosology, the science of the classification of disease and the causes of death, was in its infancy, as was the medical understanding of the cause of disease, so the accuracy of the classification of causes of death is questionable (Moriyama, Loy, Robb-Smith, Rosenberg, & Hoyert, 2011). However, these rudimentary reports provided a basic overview of disease at the population level and served as the main source of health data for nearly three centuries, finding use throughout the local response to disease (Slauter, 2011).

In 1663, John Graunt published "Natural and Political Observations Made upon the Bills of Mortality", a pioneering analysis that laid the foundation for the mathematical study of disease at the population level and vital statistics, evaluating the age distribution and causes of death,

birth rates and the growth of the population (Sutherland, 1963). Graunt was well aware of the problem of misclassification of disease, and took steps to correct for this misclassification. As Rothman described his process, "he considered the difficulty of outcome misclassification, provided an estimate of its magnitude, and used that to correct for the misclassification" (Rothman, 1996) While Graunt's work provided the basis for an approach to understanding disease at the population level, it was severely limited by the analysis of mortality, not morbidity, data.

Near real-time reporting of ill persons is necessary for timely governmental intervention to prevent the spread of disease in the population. In the United States, the first mandatory disease reporting laws were passed in Rhode Island Colony in 1741. These laws required that tavern owners report communicable diseases in their patrons to the local authorities. Two years later, Rhode Island expanded this requirement to include the reporting of smallpox, yellow fever, and cholera to local authorities by all citizens (Thacker, Qualters, & Lee, 2012).

In the 18th century, the term "surveillance" was used differently than it is used today, and was directly tied to immediate government actions in response to disease. The historical process of "surveillance" would be considered contact tracing and active monitoring today and was used to observe the health of individuals so that they could be isolated if they were to develop disease, as opposed to implementing broad quarantine measures for exposed individuals (Langmuir, 1976).

When the Tenth Amendment to the United States Constitution was ratified as part of the Bill of Rights in 1791, all powers not specifically given to the federal government, including the regulation of public health and welfare, were explicitly given to the states (Hodge Jr., 1998).

With this amendment, states were free to develop (or not develop) their own reporting requirements, processes, and responses.

In the mid-nineteenth century, the modern approach to disease surveillance was first developed by William Farr, the head of the statistical department in the General Registrar's Office of England and Wales. Farr recognized the need for a population-based approach to understanding disease and is often credited as the founder of modern disease surveillance (Langmuir, 1976). Farr described his system based on having a "staff officer" (an epidemiologist) in "every county or great city, with clerks to enable him to analyze and publish the results of weekly returns of sickness to be procured from every district", or by using the postal system to send all the result to a central officer in London (Farr, 1875).

As an early proponent of population-wide, clinician-based disease reporting, Farr wrote that it "will enable the therapeutists to determine the duration and the fatality of all forms of disease under the several existing systems of treatment in the various sanitary and social conditions of the people" (Farr, 1875). Farr's philosophical approach to surveillance laid the groundwork for the systems in place today (Susser & Adelstein, 1975), and his concept of a postal-based reporting system was the primary method of disease reporting in the United States for more than a century.

Massachusetts was the first state to implement a standardized disease surveillance similar to the one described by Farr when the Massachusetts State Board of Health developed a voluntary plan for the weekly reporting of diseases by a select group of sentinel physicians using a standard postcard in 1874 (Thacker, Qualters, & Lee, 2012; Chorba, Berkelman, Safford, Gibbs, & Hull, 1989). As described in the first report of the project, the goals were to understand morbidity, as opposed to mortality, because "An entire hamlet may be smitten by an epidemic

which makes no impression on the bills of mortality" (State Board of Health of Massachusetts, 1875). The system requested that physicians report weekly counts of 15 different conditions categorized as mild or severe diseases: bronchitis, cholera infantum, cholera morbus, croup, diphtheria, diarrhea, dysentery, influenza, measles, pneumonia, rheumatism, scarletina, smallpox, typhoid fever and whooping cough.

The reliability of his record of observations depends upon his own acuteness and judgment. He reports the presence or absence of diseases whose diagnosis is not always easy. His opinion of the nature or gravity of any case or series of cases may be quite different from that of his neighbor. What is diphtheria to one observer, is croup or simple sore throat to another; what is febricula to one, is typhoid fever to another; what is cholera infantum to one, is infantile diarrhoea to another; what is influenza to one, is bronchitis or severe catarrh to another (pp. 480-481).

The solution enacted was to rely on the expertise of the clinicians chosen for participation in their system, writing:

For this diversity there is no radical remedy. It is the source of a considerable margin of error in the registration of mortality, affecting the causes of death; it is the possible origin of a still wider range of uncertainty in the results of any scheme for registering diseases which do not afford, in their fatal termination, an additional indication for diagnosis. Our chief safe-guard is again to be found in the known skill and reputation of the observers. (State Board of Health of Massachusetts, 1875, p. 481)

While this seems like a simple, if not unsatisfying, solution, it must be viewed in the historical context of the medical profession at the time. The reputation of the observers truly was of utmost importance, as mandatory medical licensing would not be implemented in

Massachusetts until 1894, twenty years after the implementation of the disease reporting system. The medical licensing board did not require that physicians obtain a medical degree until 1915, and it was not until 1936 that the board required that the licensee had earned a medical degree from a reputable school (Hamowy, 1979). While Massachusetts did recognize that a "purely ideal system for registering prevalent sickness would involve the recording of every case of acute disease", it also recognized that it was not practical given the constraints of the system (State Board of Health of Massachusetts, 1875, p. 480).

Michigan became the first state to require the reporting diseases by all physicians in 1883. Michigan statute stated that:

Whenever any physician shall know that any person whom he is called to visit or who is brought to him for examination is infected with small-pox, cholera, diphtheria, scarlet fever, or any other disease dangerous to the public, health he shall immediately give notice thereof to the health officer, the president or the clerk of the board of health of the township, city, or village in which the sick person may be (Compiled Laws of Michigan, 1883, 1734 § 43)

The list of diseases explicitly reportable in Michigan was much smaller than was implemented in Massachusetts. However, the Michigan reporting law featured two aspects of mandatory disease reporting that are routine features of disease reporting regulations today but were not implemented in Massachusetts: application to all licensed physicians and a clause that makes unspecified "dangerous diseases" reportable.

The next phase in the evolution of the process of disease surveillance in the United States was the development of system that brought together the numerous state-based systems to produce a national picture of disease. Congress first authorized the United States Marine

Hospital Service, predecessor of the Public Health Service, to collect reports of communicable diseases (cholera, plague, smallpox and yellow fever) from U.S. consuls in foreign countries in 1878. These reports were used to establish quarantine measures to prevent disease from being imported into the United States. (Montalbano, et al., 1997) In 1893, Congress expanded the Marine Hospital Service's authority to collect information from states and local jurisdictions, and in 1902, Congress passed the "Act to regulate appointments in the Marine Hospital Service of United States", which required the Marine Hospital Service to publish forms for the standardized collection of data for morbidity, mortality and vital statistics (United States Public Health and Marine Hospital Service, 1903).

By 1901, every state had independently enacted mandatory disease reporting by clinicians to state or local health authorities. However, all states did not voluntarily participate in national disease reporting until 1928 (Thacker, Qualters, & Lee, 2012).

The final step in the evolution of the process of disease surveillance in the United States was the standardization of nationally notifiable conditions across the states. When the CDC assumed responsibility for national disease surveillance from the Public Health Service in 1946, a number of conditions were reportable with a variety of frequencies (annually, monthly or weekly).

In 1951, CDC epidemiology branch head Alexander Langmuir requested that the Association of State and Territorial Health Officers convene a meeting of state epidemiologists to determine which conditions were considered to be of national importance and should be placed under national surveillance (Centers for Disease Control and Prevention, 1996). At this meeting, forty-one conditions were placed under national surveillance and were to be reported on a weekly basis.
This meeting lead to the formation of the Council of State and Territorial Epidemiologists (CSTE), an organization that is currently responsible for annually updating the list of nationally notifiable conditions (CDC, 2014d). Based on a majority vote of member states at their annual conference (held in June), CSTE makes a formal recommendation to the CDC to add a condition to the list of nationally notifiable conditions. The Paperwork Reduction Act requires that all federal agencies obtain Office of Management and Budget (OMB) approval prior to collecting data, a process that takes at least six to nine months (typically 18 months) for approval (Coates & Aranas, 2013). Once OMB approval is granted, the condition is officially added to the list of nationally notifiable conditions.

In 1990, CDC and CSTE epidemiologists published a set of standardized case definitions to be used for the notification of nationally notifiable conditions from states to the CDC (Wharton, Chorba, Vogt, Morse, & Buehler, 1990). The authors described the purpose of the definitions as for disease notification and noted that "requirements for reporting diseases are mandated by state laws or regulations, and the list of reportable diseases in each state varies" (p. 1); however, they did not recommend that states develop standard criteria for reporting.

The list of nationally notifiable conditions has been modified annually by the members of CSTE through the addition of conditions, removal of conditions and the updating of case definitions. The most recent addition to the list of was campylobacteriosis for 2015 (Bradlek, DeMaria Jr, & Geissler, 2014), bringing the total number of nationally notifiable conditions to 108 unique infectious conditions and subconditions, five non-infectious conditions and two types of outbreaks (CDC, 2014c).

Nowhere in public health is the cliché that "all disease is local" more evident than in the history and development of disease surveillance in the United States. While national statistics are

compiled to give a larger picture of disease, the legal basis and day-to-day work of conducting disease surveillance rests at the state and local level. Adams et al. (2014) summarize the NNDSS and the United States' approach to surveillance as:

NNDSS is neither a single surveillance system nor a method of reporting. Rather, it is a 'system of systems', which is coordinated at the national level across disease-specific programs in order to optimize data compilation, analysis, and dissemination of notifiable disease data (p. 2).

Legal Basis of Disease Reporting

In the United States, the responsibility of protecting the public's health falls to the individual states and territories. As a result, the legal basis for disease reporting is distributed through numerous legal requirements throughout the country. Each state and territory has a legal mechanism for disease reporting that is unique to that jurisdiction. Some states include disease reporting in state statutes, while others require disease reporting under broad authority given to the health departments and health officers (Neslund, Goodman, Hodge Jr., & Middaugh, 2010).

This variation can also exist within a state, as counties and cities may have the legal authority to adopt their own reporting regulations in addition to existing state laws. For example, in Nevada, the legal basis for public health reporting exists through a combination of state statute, administrative code and local regulations. Nevada statutes establish the State Board of Health and provide broad power to adopt regulations (Nevada Revised Statutes 439: Administration of Public Health, 2013). The statute also provides the legal basis for the establishment of local (county or city) health departments and grants the local board of health authority to "Adopt such regulations as may be necessary for the prevention, suppression and control of any contagious or infectious disease dangerous to the public health".

In Nevada, the district health officer is given broad power to protect the public's health and may require the additional reporting of an infectious disease in addition to those specific as being reportable state-wide in administrative code (Nevada Administrative Code Chapter 441A: Infectious Disease and Toxic Agents, 2011). Based on this regulation and the broad powers to adopt public health regulations (Nevada Revised Statutes 439.366.3(d), 2013), the Southern Nevada District Board of Health adopted regulations for the reporting of diseases, which made ten additional conditions reportable in Clark County but not other counties of the state (Southern Nevada District Board of Health, 2006).

The process of adding locally-reportable conditions as was done in Clark County is unique to Nevada, as Nevada's statutes and regulations share neither a common origin nor a common evolution with the statutes regulations any of the other states. An evaluation of the reporting laws of the states and territories by Gostin, Burris, & Lazzarini (1999) found that:

The law in many states consists of successive layers of statutes and amendments, built up over one hundred years or more in response to disease epidemics. Although states sometimes follow each other in crafting legislation focused on particular topics, the health codes in their entirety have evolved independently, leading to profound variation in the structure, substance, and procedures for detecting, controlling, and preventing communicable diseases. (p. 73)

In some states, these regulations have changed very little since their introduction over a century ago. Gostin, Burris, & Lazzarini (1999) identified that in South Dakota, "The state code's chapter on disease control begins with six sections passed between 1877 and 1915, which have not been substantively amended since 1939" (p.74)

If two states choose to require that the same disease be reported within their jurisdiction, the process by which diseases are reported to the jurisdiction may be highly variable as well. A review of influenza laws initiated because of the 2009 H1N1 Influenza outbreak by Danila, et al. (2015) found that:

Reporting laws vary by state regarding which diseases must be reported, who must report, whether case laboratory specimens must be submitted, and other features. This variation could affect a national public health response to a public health emergency, because federal health officials rely on voluntary reporting of epidemiological data from states to the Centers for Disease Control and Prevention (p 13).

While half the states in Danila's study required the reporting of influenza-associated pediatric mortality, only ten percent required the reporting of all age influenza-associated mortality. While most states required reporting by physicians and laboratories, some also required that coroners and medical examiners had to report (as deaths were not required to be reported in all states). Twenty percent of states required reporting of suspect cases in addition to confirmed cases. In summary, the study found wide variation in how states require the reporting of influenza. Similar studies have not been reported on the legal reporting requirements of other diseases.

Bias

One key attribute of an effective surveillance system is that it accurately represents the occurrence of the condition of interest in the population under observation. While it is unrealistic to expect that every case of disease in population will be identified by the system, the system should consistently identify a subset of representative cases over time (German, et al., 2001). Kimball, Thacker and Levy came to a similar conclusion, noting that "Certainly underreporting

is not a problem if reported cases truly reflect disease activity and are obtained in a timely manner" (1980, p. 166).

Infectious disease reports are frequently described as being the "tip of the iceberg" in that the reported cases are only a small fraction of the total cases of disease in a population (Louisiana Office of Public Health Infectious Disease Epidemiology Section, 2014; Hunter & Scallen, 2010; Simcoe Muskoka District Health Unit, 2010). The unreported cases are not one homogeneous group, and consist of subgroups of undiagnosed, untested, and unreported cases. Each step between the occurrence of disease and the reporting of the case to the public health jurisdiction is an opportunity for bias to be introduced into the system, and differences in these biases between reporting jurisdictions can increase the difficulty of comparing results across multiple jurisdictions.

Once a disease occurs in a person, that person must seek care for their illness, and the proportion of people in a population seeking care varies by condition and severity. Patients will not seek care for a number of reasons, including being unemployed, being uninsured and not having a healthcare provider (Biggerstaff, et al., 2014). The proportion of cases tested for a particular disease (which is required of nearly all conditions on the nationally notifiable conditions list) also varies by condition and the severity of clinical presentation. It may also vary with the clinician's knowledge of the incidence in the population; for example, a clinician may not elect to test for influenza at the height of influenza season given the increased predictive value positive of a clinical diagnosis. If a test is ordered, it must detect the presence of the disease, which is dependent on the sensitivity of the test. Finally, the laboratory result or clinical diagnosis based upon that laboratory result must be reported to the public health authority (Reed, et al., 2009).

Reasonable assumptions can be made about the consistency across reporting jurisdictions at each of these steps. Care-seeking behavior should be consistent across jurisdictions in the United States. A mathematical modelling study on 2009 H1N1 influenza reviewed several published studies on care-seeking behavior and found that roughly 50% of people sought care for influenza across multiple jurisdictions and settings (Reed, et al., 2009). The same consistency was identified for clinician testing for influenza, and the sensitivity of testing is consistent across jurisdictions, as it is based on the methodology used for testing itself.

Reporting by clinicians and laboratories appears to be consistent across states. A 2002 analytic literature review of 33 studies conducted between 1970 and 1999 found that disease reporting completeness is most highly correlated with the type of disease being reported, with completeness ranging from 9% to 99%. The review also found that reporting completeness varied by condition but was generally unaffected by geography (Doyle, Glynn, & Groseclose, 2002). The results of this study must be interpreted carefully, as it included multiple studies with small sample sizes (as few as 16 cases), did not represent the breadth of types of diseases that were reported, evaluated both active and passive surveillance approaches and treated mortality and hospitalization reporting as being the same as morbidity reporting. However, there is no indication that larger sample sizes would identify significant geographic differences among the relevant studies.

The identified reasons for underreporting included a lack of awareness that there was a legal requirement to do, a lack of knowledge about how to report and to whom to report, confidentiality concerns, and a reliance on someone else (such as a laboratory) to file the legally-mandated report. These reasons were the same ones identified by Silk and Berkelman (2005),

and the strategies Silk and Berkelman propose to improve clinician reporting would apply irrespective of geography

As the Nationally Notifiable Diseases Surveillance System is a "system of systems", the representativeness of the system and the types and extent of bias must be consistent across those jurisdictions for data to be comparable across different reporting jurisdictions. The need for consistent data was described in early surveillance system proposals of the late 19th century, but remains an unresolved issue over a century later.

Development of Case and Reporting Definitions

A survey conducted by CSTE in 1984 found that "substantial variations in case definitions of reportable diseases, criteria for counting as a case, and sources of surveillance" and advocated for the development standardized case definitions for all nationally notifiable conditions (Sacks, 1985).

In 1990, a set of standardized case definitions were released for use by local and state health departments in evaluating disease reports to determine if the CDC should be notified (Wharton, Chorba, Vogt, Morse, & Buehler, 1990). While the authors expressed the hope that "the incidence of reported diseases in different geographic areas may be more meaningfully compared", standardized case definitions do not completely remedy this problem. Sacks (1985) stated that people using the NNDSS data "need to be aware of the limitations of these data because of the differences in case counting and ascertainment practices" (p. 1422); the case definitions solved the issue of differences in case counting, but not in case ascertainment.

An update to the case definitions was published in 1997 based on changes approved by CSTE. Both the 1990 publication (Wharton, Chorba, Vogt, Morse, & Buehler, 1990) and 1997 publication (Koo, Wharton, & Birkhead, 1997) provides a brief summary of the need for

surveillance; differences in the language between these two publications hint at changes in the way the view of surveillance had changed. In 1990, the basic needs of the system were described as "uniformity, simplicity, and brevity". As the demand for data on notifiable conditions increased and the desire to have timely data in order to be able to respond to cases of disease, this description changed to "uniformity, simplicity, and timeliness" in 1997.

More importantly, one change in phrasing hints at how epidemiologists saw the role of these case definitions in public health. In 1990, readers were cautioned not to use the case definitions as "sole criteria for establishing clinical diagnoses, determining the standard of care necessary for a particular patient, setting guidelines for quality assurance, providing standards for reimbursement, or initiating public health actions". In 1997, the phrase "or initiating public health action" was removed, blurring the line between definitions used for case notification and criteria used for case reporting by clinicians and laboratories. This is reflected in disease reporting laws in Nevada, where regulations passed in 1992 adopted the national case definitions and required clinicians to report "cases" and "suspected cases" of disease (Nevada Administrative Code Chapter 441A.200, 2011).

In 2007, CSTE passed a position statement which provided a standard format for placing diseases on the NNC list. This included a requirement that authors provide the criteria used to determine when a clinician, laboratory or other reporting entity should make a report to the health authority (Macdonald, 2007). As a result of this position statement, all diseases on the NNC list were reevaluated, reporting criteria were added to the national case definition, and all newly-added conditions were required to include the same criteria. Although the reporting criteria have been in place for several years, no published studies have been identified that have evaluated their inclusion in state reportable disease criteria.

Evaluation of the National Notifiable Disease Surveillance System

In 2001, the CDC updated guidelines for the evaluation of public health surveillance systems in order to account for changes in public health informatics, including data exchange and system integration (German, et al., 2001). However, as a "system of systems", NNDSS cannot be fully evaluated using the CDC's guidelines, as many evaluation tasks are not suited to the distributed nature of the system. Additionally, the guidance has no provision for evaluating the "system of systems" approach. For example, the guidance assumes that the legal authority for implementation of the system is consistent across all portions of the system, and does not provide for the evaluation of differences across states.

In August of 2011, the CDC initiated an external functional evaluation of the all aspects of the NNDSS. The first phase was conducted within CDC to evaluate the business goals, processes and critical shortcomings of the system, as well as to make recommendations for improvement that could be made at the CDC (Smith, Kriseman, & Kirkwood, 2011). They found that the NNDSS lacked "a consistent, national (both within and outside CDC), long-term oversight or governance mechanism to guide NNDSS strategically" (p. 3). Much of this inconsistency is due to the system serving different purposes for the local, state and federal stakeholders. Smith, Kriseman and Kirkwood (2011) described these differences as

State and local health departments see this reporting system's main function as the means to receive actionable information to allow them to intervene and manage disease, and secondarily to report to CDC, produce reports of communicable diseases, and conduct analytic studies. CDC staff see NNDSS primarily as a mechanism of receiving accurate and timely information on notifiable cases for national surveillance tracking, special studies, and, where indicated, reporting to the World Health Organization. (p. 9)

While this analysis hints at the underlying reason for interstate differences in the NNDSS, it does not specifically address the issue of the impact of disease reporting to the states.

The second phase of the evaluation "addressed the needs and perspectives of state and local health departments about infectious disease surveillance within NNDSS" (Council of State and Territorial Epidemiologists, 2012). The major focus of the evaluation was the technical framework of the National Electronic Disease Surveillance System (NEDSS), which is the umbrella term encompassing systems used to conduct investigations and notify CDC of confirmed and probable cases. Respondents identified confusion about the meaning of acronyms NNDSS and NEDSS as an issue; the survey did not help clarify the matter, as it was more of an evaluation of the NEDSS than NNDSS, despite the name of the report. As in phase one, phase two did not address the underlying legal framework for reporting or any of the criteria used for disease reporting within a state or local health department. Also as with phase one, the assessment provided little relevant analysis of the underlying theoretical framework of NNDSS.

Evaluation of State Reporting Practices

Research on state reporting requirements has not been widely conducted and has been limited to determinations of which diseases are reportable in which states (Fowler, 1944; Rousch, Birkhead, Koo, Cobb, & Fleming, 1999; Jajosky, et al., 2011). As disease reporting occurs at the state and local level, the reporting requirements of neighboring jurisdictions are of little interest to clinicians and laboratories, and summary articles of disease reporting practices are of little value to the mandated reporters.

Since 2008, CSTE and CDC have conducted the State Reportable Conditions Assessment (SRCA), an annual joint survey to determine which diseases are legally reportable in each statelevel jurisdiction. The SRCA surveys state epidemiologists to determine if a given condition is

reportable within the jurisdiction, the groups required to submit a report, and the timeframe in which reports must be submitted (Council of State and Territorial Epidemiologists, 2013). As not all conditions are reportable in all states, the results of the survey are used to calculate the population denominator for calculating disease-specific rates (Ferland & Jajosky, 2011).

The SRCA has been evaluated in only one published article; the most significant finding was that many states do not explicitly require that certain diseases be reported, but rather rely on implicit reporting requirements, which could pose a challenge for the automation of case reporting. Some diseases are reportable under broad categories such as "rare diseases of public health importance"; for example, Coccidioidomycosis is implicitly reportable in 25% of the states and territories as a rare disease (Jajosky, et al., 2011).

The concerns about implicit reporting of disease raised by Jajosky are of concern to a joint CDC/CSTE/Association of Public Health Laboratories initiative, the Reportable Condition Knowledge Management System (RCKMS), a project to create a machine-readable database of all permutations of disease reporting in order to facilitate automated electronic disease reporting (Altamore, Conn, Staes, & McGarvey, 2013). If the RCKMS is ultimately successful, it will still not address the problem of different disease reporting criteria resulting in data that cannot be compared across states. While the system does catalog the reporting requirements by state and is intended be used by clinicians, hospitals and laboratories to determine what is reportable in a jurisdiction, it is not intended to eliminate differences between states or to create a standardized technical reporting framework.

Jajosky et al. (2011) also identify a limitation of the design of the SRCA: "although SRCA supports information needs for surveillance, this assessment does not support the realtime needs of reporting entities" (p. 256). While the SRCA collects data about reportable disease

in a standardized format, such a format is not made available by states to clinicians, laboratories and other reporting entities and may be up to interpretation by clinicians.

Additionally, CDC uses a hierarchy in the evaluation of SRCA data to determine if a particular disease is reportable; for example, if "poliovirus (not further specified)" is listed as being reportable, a more specific disease such as "poliomyelitis, paralytic, vaccine associated" would also be considered to be reportable (Jajosky, et al., 2011). While this designation may be easily understandable to the epidemiologists that work with polio, subtle differences between the conditions may not be as obvious to clinicians and may result in over- or under-reporting.

Not included in the 2008 SRCA, but included in later SRCA surveys, are broad, nonspecific categories that might result in the identification of a case at the state or local level. For example, if the law requires that all cases of "acute hepatitis" be reported and the health department then performs testing to determine which virus is causing the infection, cases of acute hepatitis A, B, or C could be discovered. The same is true for acute flaccid paralysis case reports resulting in the identification of polio or hemolytic uremic syndrome reports resulting in the identification of Escherichia coli O157:H7.

A major limitation of the SRCA is that it views state reportable diseases from the perspective of the public health department and not the clinician or other required reporter. States are encouraged to have subject matter experts complete the sections related to their expertise (Council of State and Territorial Epidemiologists, 2013), which may result in a biased view of reporting requirements especially within broad categories that make a number of conditions implicitly reportable. As the system is passive and is dependent is on clinicians to make the effort to report disease, a better evaluation of the system would be based on the clinician's perspective of what is reportable.

Use of the Data

While little research on the processes of disease reporting through the NNDSS has been conducted, data generated by the system are widely published and serve as the basis for scientific inquiries, policy discussion and funding decisions. Data from the NNDSS are published weekly in the Morbidity and Mortality Weekly Report, the CDC's journal of public health surveillance, in a section entitled "Notifiable Diseases and Mortality Tables". This table provides weekly provision counts of nationally notifiable diseases submitted to the CDC. The final issue for each year (typically published 18 to 24 months after the completion of the year) is the finalized "Summary of Notifiable Diseases" (Teutsch, 2010).

The NNDSS serves as the primary data source for numerous articles. Recent example of the uses of NNDSS data include studies of the descriptive epidemiology of Hansen's Disease (leprosy) in the United States over a 15-year period (Nolen, et al., 2014), a description of increasing incidence in primary and secondary syphilis, especially in men who have sex with men (Patton M. E., Su, Nelson, & Weinstock, 2014), and an estimation of the number of actual acute hepatitis cases based on reported cases (Klevens, Liu, Roberts, Jiles, & Holmberg, 2014). NNDSS data were also used widely as performance metrics for the CDC in Director Tom Frieden's Congressional justification of CDC's FY2015 budget, including the number of incident cases of HIV, hepatitis A and hepatitis B, and the incidence rates of gonorrhea, syphilis and tuberculosis, Escherichia coli O157:H7 infection, listeriosis and salmonellosis (Centers for Disease Control and Prevention, 2014a).

Summary

Guidelines for the use of NNDSS data specifically issue the warning that "Surveillance practices, policies, priorities, and resources vary from state to state. Therefore, one should use

caution when making state-to-state comparisons of disease incidence" (Centers for Disease Control and Prevention, 2001). Given the wide range of uses of the NNDSS data, a better understanding of the limitations of the process of data collection is of vital importance to the interpretation of a core set of data used in public health in the United States. Variation in the reporting process between states creates an issue that is central to this study: differences in disease reporting requirements among states can lead to selection bias in the inclusion of potential cases of disease. While this bias would be consistent for a given state over time (assuming that their reporting process was consistent), disease from different states may not be directly comparable and may lead to misleading conclusions.

When Ida Sherman and Alexander Langmuir, the first heads of statistics and epidemiology at the newly-formed CDC made the case for national disease reporting, they described one of the limitations of clinician-based passive surveillance as the "incomplete etiological definition of reportable disease entities" and stated that the numerous limitations "may be eliminated gradually through a study of the particular disease in specific areas, but other flaws will probably always remain" (Sherman & Langmuir, 1952). To this day, the impact of state-based differences in disease reporting is still not well described.

Chapter 3 – Methods

Introduction

The NNDSS provides a number of recommendations to states on the establishment of reportable conditions. While it does not require that any conditions be made reportable within the state, it does provide guidance on how states can ensure consistency of reporting by providers to the state and local health departments and notification of disease to the CDC if a state chooses to make a disease reportable. The overall purpose of this study is to describe the implementation of disease reporting within the United States at the state/territorial level, explore the factors associated with differing implementations and to describe how the varying implementation affects the validity of interstate comparisons of disease.

Research Questions and Hypotheses

This study consisted of four main research questions focusing on the NNDSS. The research questions were independent of each other, and each required separate data collection. For some research questions, the variables were separated into high and low dichotomous categories based on a comparison to the group median.

Research Question One

For 2015, do all state-level public health jurisdictions require the reporting of conditions under any category of reporting (i.e. explicitly, more broadly, or more narrowly) on the 2015 nationally notifiable conditions list?

Hypothesis for Question One

Ho: For 2015, all state-level public health jurisdictions do not mandate the reporting of all conditions under any category of reporting on the 2015 nationally notifiable conditions list.

Ha: For 2015, all state-level public health jurisdictions mandate the reporting of all conditions under any category of reporting on the 2015 nationally notifiable conditions list.

Research Question Two, Part One

What state-specific factors, if any, are associated with a state including a greater than median number of 2015 nationally notifiable conditions on their respective state's 2015 reportable conditions list?

Hypothesis for Question Two, Part One

- Ho: No state-specific factors are associated with a state including a greater than median number of 2015 nationally notifiable conditions on their respective state's 2015 reportable conditions list.
- Ha: One or more state-specific factors are associated with a state including a greater than median number of 2015 nationally notifiable conditions on their respective state's 2015 reportable conditions list.

Research Question Two, Part Two

What condition-specific factors, if any, are associated with a condition being including on a greater than median number of 2015 state reportable conditions lists?

Hypothesis for Question Two, Part Two

- Ho: No condition-specific factors are associated with a condition being included on a greater than median number of 2015 state reportable conditions lists.
- Ha: One or more condition-specific factors are associated with a condition being including on a greater than median number of 2015 state reportable conditions lists.

Research Question Three

Do a majority of state-level public health jurisdictions add conditions to their list of statereportable conditions within 18 months after they have been added to the list of nationally notifiable conditions?

Hypothesis for Question Three

- Ho: A majority of state-level public health jurisdictions do not add conditions to their list of state-reportable conditions within 18 months after they have been added to the list of nationally notifiable conditions.
- Ha: A majority of state-level public health jurisdictions add conditions to their list of state-reportable conditions within 18 months after they have been added to the list of nationally notifiable conditions.

Research Question Four

Do state-level public health jurisdictions utilize the same reporting criteria as in the official reporting recommendation for diseases reportable within the jurisdiction?

Hypothesis for Question Four

- Ho: Reporting jurisdictions mandate the reporting of conditions on the nationally notifiable conditions list utilizing the same reporting criteria as in the recommendation.
- Ha: Reporting jurisdictions do not mandate the reporting of conditions on the nationally notifiable conditions list utilizing the same reporting criteria as in the recommendation.

Study Population

The subjects included in descriptive portions of this study were the state-level public health reporting jurisdictions in the United States that directly notified the CDC of notifiable conditions in 2015. These jurisdictions included the 50 states, Washington DC, and New York City, NY. For the analytic portions of this study, Washington DC and New York City, NY were excluded as they were not included in the state-level evaluations being used as sources of data. The five US territories (Guam, Puerto Rico, the US Virgin Islands, American Samoa and the Commonwealth of Northern Mariana Islands) were also excluded from all analyses, as they have historically not fully participated in the NNDSS.

Data Sources

The main sources of data for this project were the list of Nationally Notifiable Conditions on the CDC website, documents related to the NNDSS posted on the CDC website, CDC publications of weekly or annual disease statistics, and individual reporting jurisdiction websites listing the state-reportable conditions. Additionally, the CSTE position statement (and official CDC response to the position statement) that added the condition to the list of nationally notifiable conditions was used as a data source and as documentation to resolve any issues with the interpretation of the notifiable condition.

Data Management and Analysis

State reportable condition data were identified on state and county health department websites and hand-entered onto paper data collection forms. The data from the paper forms were manually entered into Microsoft Excel 2013 then imported into a Microsoft Access 2013 database developed for the project. Data were compared against the state websites to identify and correct any data entry errors. Condition names were manually standardized to the names on the

NNC list, and all nationally notifiable conditions recorded as not being reportable in a state were confirmed by a review of the state's reportable condition list, state regulations and state disease statistics. Data analysis and visualization was performed using Microsoft Excel 2013 and SPSS 21.

Research Question One Methods

To understand the general reporting structure in each state-level jurisdiction (state), the section of the state health department's website pertaining to the reporting of disease was identified through internet searches and evaluated to answer the following questions:

- Did the state provide the required reportable conditions in a summarized (list) format (as opposed to a reference to a legal document)?
- Did the state provide legal citations for the reporting of disease?
- Did the state provide a list of the standard codes for clinician reporting, e.g., Systematized Nomenclature of Medicine (SNOMED), International Statistical Classification of Diseases and Related Health Problems version 9 (ICD9) or version 10 (ICD10)?
- Did the state provide a list of the standard codes for laboratory reporting, e.g., Logical Observation Identifiers Names and Codes (LOINC), SNOMED?
- Did the state provide forms for the reporting of suspect cases?
- Did the state provide an on-line method for the reporting of suspect cases?
- Did the state provide instructions on how disease reports should be submitted?
- Did the state have a separate reportable condition list for laboratories and clinicians?
- When was the list last updated?
- When was the website last updated?

- Did the state provide a disease reporting poster (either directly printable or that could be ordered)?
- Was the state's reporting website up to date (as compared to the date the list was last updated)?

Additionally, the 2015 state reportable disease list from each of the 52 state-level jurisdictions was collected from the individual state health department websites, when available. If the state website did not provide such a list, the list was identified from local public health jurisdictions within that state.

The list of nationally notifiable conditions as of January 1, 2015, was abstracted from the Centers for Disease Control and Prevention's NNDSS website. Healthcare-acquired infections were excluded from this analysis, as they are reported through a separate system.

Each state reportable condition list was reviewed to determine which nationally notifiable conditions were reportable in the state. The reporting requirement was classified as:

- Explicit: the NNC was explicitly listed as a reportable condition for the state.
- Broader: the NNC was listed as part of a broader category of explicitly reportable conditions within the state. For example, pediatric influenza deaths would be classified as "explicit, broader" if all influenza deaths were reportable in the state. An NNC was not classified under very broad categories such as "diseases of public health concern" without further specification.
- Narrower: only a subset of the NNC was explicitly reportable in the state. As an example,
 Spotted Fever Rickettsiosis would be classified as "explicit, narrower" if the state
 required the reporting of Rocky Mountain Spotted Fever.

• Not Reportable: the condition was not explicitly reportable within the state under one of the above categories.

For each nationally notifiable condition reportable in a state, the timeframe in which it must be reported, and the people or organizations who must report conditions were also identified.

State-reportable conditions that were not nationally notifiable were identified from the states' reportable disease list, standardized and entered into the database as well.

Conditions that have been removed from the nationally notifiable conditions list were identified by evaluating CSTE position statements, CDC disease reports and published articles about the NNDSS.

Descriptive statistics for research question one were calculated for both states and conditions, including the overall state reporting requirements, disease reporting by state and population, timeframes for state reporting, required reporting entities and state reporting of NNCs, former NNCs, and non-NNCs.

Research Question Two Methods

For research question two, part one, state statistics and public health rankings were collected for the 50 states (excluding Washington D.C. and New York City) as independent variables, including:

- From the report "America's Health Rankings":
 - Overall state health ranking (United Health Foundation, 2014)
 - Physicians per 100,000 population (United Health Foundation, 2014)
 - From the Trust for America's Health/Robert Wood Johnson Foundation:
 - FY 12-13 State public health funding and per capita funding (Levi & Segal, 2014)
 - FY 12-13 CDC public health funding and per capita funding (Levi & Segal, 2014)

- From the United States Census Bureau population estimates and American Community Survey:
 - Population (United States Census Bureau, 2014a)
 - Population density (United States Census Bureau, 2014b)
 - Educational attainment (United States Census Bureau, 2012)
 - From the National Immunization Survey:
 - 2013 4:3:1:3:3:1 immunization coverage (Centers for Disease Control and Prevention, 2013)
- From the Emerging Infections Program:
 - 2015 program participation (Centers for Disease Control and Prevention, 2015).

For research question two, part one, the number of NNCs and the number of non-NNCs reportable in each state were calculated from the data collected and analyzed. State-specific factors and the number of reportable conditions were categorized into high and low dichotomous categories based on a comparison to the group median. Statistical analysis was conducted using SPSS 21.0 for Windows. Chi-square tests of independence were conducted for each state-specific factor and number of reportable conditions. Additionally, correlation coefficients were calculated for the strength of association between state-specific factors and number of reportable conditions. Additionally, correlation coefficients were conducted for the strength of association between state-specific factors and number of reportable conditions.

For research question two, part two, condition characteristics were determined for each NNC and categorized as dichotomous (yes/no) variables, including:

- Inclusion as a "Category A" bioterrorism condition by the CDC (Meselson 2002).
- A condition being vaccine-preventable.

• The CDC notification urgency category (Centers for Disease Control and Prevention 2014e).

The number of states the NNCs were reportable in were categorized into dichotomous high and low categories based on a comparison to the group median. Statistical analysis was conducted using SPSS 21.0 for Windows. Chi square tests of independence were conducted for the strength of association between each condition-specific factor and number of states in which the NNC was reportable.

Research Question Three Methods

Conditions added to the NNC between 1992 and 2012 were identified using CSTE position statements, CDC weekly and annual summaries published in the Morbidity and Mortality Weekly Report and NNDSS documentation from the CDC website. Conditions were excluded from further analysis if they were not included in CDC summary publications with state-specific data (i.e. counts are only reported in aggregate for all states) for the necessary time periods, or were subcategories of a larger parent category that may not require changing of disease reporting regulations, for example, if deaths from an existing NNC were added to the NNC list, or were not reported through NNDSS but were reported through other mechanisms or systems.

For each condition included, the MMWR publications and summaries of nationally notifiable diseases for the year in which the condition was added and subsequent years was reviewed to determine if and when the disease was added to the state's list of reportable diseases during the study period. The MMWR Summary of Notifiable Diseases for the year in which the condition was added to the NNC list to determine in which states it was reportable during the first year it was nationally notifiable (the summary lists the total number of cases in each year,

and indicates states for which the condition was not reportable). For states in which the disease was not reportable in the first year, subsequent annual summaries were iteratively reviewed until the year it was made reportable in the state was identified. As 2013 and later summaries had not been published at the time of the data collection, the MMWR report for the first week of July in 2013 through 2015 was reviewed to determine if the condition was reportable in those years. A condition was considered reportable for a state if that state had reported any cases in that year. CDC requires that a condition must be reportable for at least six months to be considered reportable for the year; a condition reportable in early July would meet this threshold, and those made reportable after that point would not.

This six-month requirement was use to set the 18-month cutoff for this research question. In order to be considered reportable in the year it was added to the list, it would need to be added to the state's reportable conditions list within the first six months of the year. Given that states typically follow a complicated legal process to make the condition reportable, allowing only six months to complete this process is unreasonable expectation. An 18-month cutoff was selected to provide states an opportunity to add the condition to their reportable list, and would result as the condition being listed as reportable by the CDC in either the year it was added to the national list or the subsequent year (year zero or one).For each selected condition, the time to addition to a state reportable list was calculated and evaluated against the cutoff.

Research Question Four Methods

Four nationally notifiable conditions were selected for detailed analysis based on their frequency of reporting, importance to public health and the complexity of recommended criteria for reporting. These selected conditions were: elevated blood lead levels, influenza-associated pediatric mortality, Shiga toxin-producing Escherichia coli, and Tuberculosis.

The most recent CSTE position statement for each NNC was downloaded from the CSTE website. State reportable condition list information, disease reporting guides and state regulations were reviewed for each state, and the recommendation set forth in the CSTE position statements for the reporting of a disease to a state was compared against the state's reporting requirements.

For this project, a "reporter type" is defined as the category of individuals or organizations that, because of their professional license or function (e.g., physicians, nurses, hospitals, laboratories), must submit a report of a condition to a state or local health department when the condition is identified. The reporter types in each state were compared to the national recommendation and were categorized as:

- Not reportable in the state.
- More reporter types were required to report than the national recommendation.
- The same reporter types were required to report as the national recommendation.
- Fewer reporter types were required to report than the national recommendation.

They were also categorized for clinical and laboratory criteria that necessitate a report as:

- Not reportable in the state.
- Broader criteria to initiate a report than the national recommendation.
- The same criteria to initiate a report as the national recommendation.
- Narrower criteria to initiate a report than the national recommendation.
- The condition was reportable, but the criteria to initiate a report are not provided by a state.

Descriptive statistics were calculated for each selected NNC, including the number and percent of states requiring reporting of the NNC, grouped by the above-listed classifications.

Human Subjects Protections

The Code of Federal Regulations (CFR) governing the protection of human subjects defines a human subject as follows:

Human subject means a living individual about whom an investigator (whether

professional or student) conducting research obtains

(1) Data through intervention or interaction with the individual, or

(2) Identifiable private information (Protection of Human Subjects, 2009)

All data collected in this study pertained to the process of disease reporting and did not include actual data collected from human subjects. As such, the data collection in this project was not covered by 45 CFR part 46 (see Figure 1), and therefore it did not require review or approval by the Institutional Review Board at the University of Nevada, Las Vegas for the protection of human subjects.

Chapter 4 – Results

Question One: General Characteristics of State Reporting Requirements

Of the 52 state-level health departments (states) evaluated, 51 (98%) provided their reportable conditions in a list format either on the state's website or in a downloadable document. The District of Columbia provided a link to the regulations specifying which conditions must be reported but did not provide a reporter-friendly version of the list of reportable conditions. It also did not provide the list of reportable conditions as part of the form provided for disease reporting. While Nevada provided a list of reportable conditions on the state website, the list was last updated in 2004 and was out-of-date compared to the disease reporting form (which included a more recent, but still out-of-date, list).

Forty-one states (79%) provided the list in a poster format that could be displayed in the offices of healthcare providers. Thirty-three states (63%) provided separate lists for both clinicians and laboratories or indicated specific laboratory reporting requirements within the same document; the remaining 19 states (37%) had a combined list for all types of reporters but did not list specific requirements for laboratories. All states except Illinois (98%) made reference to the specific laws mandating the reporting of disease.

Several states listed the results from a particular test as making a condition reportable; no state did so throughout their reporting requirements for all conditions, and the test results were only listed for the occasional condition (for example, a positive PPD test requiring the reporting of latent tuberculosis). Additionally, no state provided a list of LOINC or SNOMED codes that indicated which tests necessitated the reporting of conditions through electronic laboratory reporting. Only Missouri listed the ICD-9 and ICD-10 codes for the conditions reportable by clinicians for a majority of conditions.

While 42 states (81%) provided instructions on how reports were to be filed with the health department, 8 of these states (19%) did not provide forms to be used in the reporting process. One state, Indiana, provided a form for the reporting of disease but did not describe the process of submitting the form and provided neither an address nor a fax number. Only 14 states (27%) described an online method for submitting reports of notifiable conditions.

Over half the states have updated their reportable conditions list within the past two years and 85% have updated their list within the last five years. Only two states, Kansas and Minnesota, have not updated their lists within the past eight years. Figure 2 provides the full distribution of the years since state reportable conditions lists were updated. The majority of states did not list the date the disease reporting website was last updated, with only 14 (27%) providing that information. Of the 14 webpages with dates, five (36%) were not listed as being updated since the date of the last revision of the state's reportable condition list.

Question One: State Condition Reporting Requirements

Descriptive epidemiology of state reporting requirements

Only one state, Louisiana, required the reporting of all nationally notifiable conditions in 2015. The number of NNCs reportable in each state ranged from 61 to 80 (76% to 100%), with a mean of 71.8. The distribution of the number of NNCs reportable by states is represented in Figure 3. Individual state results are presented in Table 1.

Nationally, 86% of reportable NNCs were explicitly reportable in states where they were required to be reported, 11% were reportable as part of a broader category of conditions (such as hepatitis C, acute and hepatitis C, past or present both being reported as part of the larger parent category of hepatitis C), and 3% required a subset of disease to be reported (for example, the NNC has no age restriction but is only reportable in children in the state).

States required disease reporting using a total of 28 different timeframes; individual states used an average of 4 different timeframes (range: 2 to 6). Only three of these timeframes were used by a majority of states: 43 states (83%) required immediate reporting of some conditions, 42 states (81%) required reporting of cancer within 6 months, and 31 states (60%) required reporting of numerous conditions within one day. This distribution of disease reporting timeframes is presented in Figure 4.

The timeframe for the most urgent category of reporting is "immediately" for 42 states (81%), "2 hours" for one state (2%), "4 hours" for one state (2%) and "1 day" for 8 states (15%). Twenty-one NNCs (26%) must be urgently reported in the majority of states in which they are reportable. These conditions are presented in Table 2.

Seventy-two categories of reporters are required to report disease throughout the country. Laboratories are required to report conditions in all states, and three additional categories of reporters are required to report conditions in a majority of states; 41 states (79%) require physicians to report, 29 (56%) require hospitals to report, 28 (54%) require the broad category of healthcare providers to report, and 21 (40%) require the broad category of healthcare facilities to report. Fifty-eight of the 72 categories of reporters are required to report in ten or fewer states; 19 categories of reporters (26%) are required to report conditions in only one state, and 20 categories of reporters (28%) are required to report conditions in two states.

Descriptive epidemiology of condition reporting

Twenty-four of 80 NNCs (30%) were explicitly reportable in all 52 state-level jurisdictions. Ten additional conditions were reportable in all jurisdictions using any reporting criteria, for a total of 34 NNCs (43%) that were required to be reported in all states. These conditions are listed in Table 3.

Fifty-four NNCs (68%) were reportable in at least 90% of states and 69 NNCs (86%) were reportable in at least 80% of states. Only four conditions (5%) were reportable in fewer than half the states; these conditions included carbon monoxide poisoning, silicosis, coccidioidomycosis and nonparalytic poliovirus infections. Thirty-seven conditions (46%) were explicitly reportable in 90% of states. The complete list of the number of states requiring the reporting of an NNC by reporting type is provided in Table 20. Information on the reporting practices for each nationally notifiable condition is provided in Figures 17 through 96 found in Appendix C: Nationally Notifiable Condition State Reporting Requirements.

For eight NNCs (10%), the majority of states requiring reporting did so as part of a broader category of disease rather than making the disease explicitly reportable on its own. Six additional conditions (8%) were reportable as part of a broader category in at least 40% of states. These conditions are presented in Table 4.

The only NNC for which the majority of states required the reporting of a narrower category of disease was spotted fever rickettsiosis; 26 of 48 states (54%) that required the reporting of spotted fever rickettsiosis did so by requiring the reporting of Rocky Mountain spotted fever rather than broader category. Twenty-two of 49 states (45%) that required the reporting of Hantavirus infection did so as the narrower condition Hantavirus pulmonary syndrome. Sixteen of 51 states (31%) did not require the broad reporting of the arboviral disease, but rather required the reporting of one or more individual arboviral diseases such as West Nile virus infections or St. Louis encephalitis virus infections.

Descriptive epidemiology of disease reporting by population.

The percent of the United States population for which a disease must be reported was similar to the percentage of states in which a disease must be reported, with an average difference between the two measures of 1%. Fifty-nine NNCs (74%) were reportable in states covering at least 90% of the United States population and 67 NNCs (84%) were reportable in states covering at least 90% of the United States population. Three conditions (4%) were reportable in states covering less than half the United States population; these conditions are carbon monoxide poisoning, coccidioidomycosis and silicosis.

The average difference between the percentage of states in which an NNC was reportable and the percentage of population for which an NNC was reportable is 1.1%, with a standard deviation of 3.9%. Only six conditions (8%) had a difference of greater than two standard deviations above or below the mean; these conditions are presented in Table 5.

Reporting of non-notifiable conditions

A total of 163 unique conditions not found on the NNC list were reportable in states. This included chikungunya, which was recommended for addition to the 2015 NNC list but had not been officially added as had not completed the Office of Management and Budget approval process. Six conditions not on the NNC list were reportable in a majority of states and are presented in Table 6. This includes AIDS, which was reclassified on the NNC list as stage III HIV disease for 2014 but is still listed as a reportable condition in 37 states (71%). Sixty-three conditions (39%) were only reportable in a single state, 113 (69%) were reportable in five or fewer states, and 142 (87%) were reportable in ten or fewer states. The distribution of the number of states requiring the reporting of non-NNCs is presented in Figure 5.

The number of non-NNCs required to be reported in a state ranged from 7 to 39, with an average of 17.6 conditions. The distribution of the number of non-NNCs reportable in states is presented in Figure 6.

Reporting of former nationally notifiable conditions

Between 1951 and 2014, fourteen conditions were removed from the NNC list. Four of these conditions, pneumonia and three types of post-infection encephalitis, were not reportable in any state in 2015. Nine former nationally notifiable conditions were still reportable in 2015 in one or more states, although only one condition, group A streptococcal infection, was reportable in a majority of states. The required reporting of former NNCs is presented in Table 7. Of note is that influenza was still required to be reported in 9 states despite being removed from the list in 1951.

State reporting of all conditions

On average, states required 89 conditions to be reported including NNCs and non-NNCs (average = 89.4, median = 87.0, mode = 85 and SD = 10.2). The distribution of the number of reportable conditions in states is presented in Figure 7.

Question one summary

States varied widely in the number of conditions required to be reported, and only one state required the reporting of all nationally notifiable conditions. The null hypothesis that all state-level public health jurisdictions do not mandate the reporting of all conditions under any category of reporting on the 2015 nationally notifiable conditions list was supported.

Question Two, Part One: State-Specific Factors

No state factors were found to have a statistically significant association with the number of nationally notifiable conditions (Table 8), and no state factors had a statistically significant association with the number of non-nationally notifiable conditions reportable in a state by chisquare testing.

Question two, part one summary

No state-specific factors were associated with a higher number of nationally notifiable conditions being reportable in a state. The null hypothesis that no state-specific factors are associated with a state including a greater than median number of 2015 nationally notifiable conditions on their respective state's 2015 reportable conditions list was supported.

Question Two, Part Two: Condition-Related Factors

No condition-specific factors were found to have a statistically significant association with the number of states in which the nationally notifiable condition was reportable. Pearson X2 values and corresponding p-values are presented in Table 9.

Question two, part two summary

No condition-specific factors were associated with a condition being including on a greater than median number of 2015 state reportable conditions lists, thus the null hypothesis is supported.

Question Three: Timely Addition of NNCs to State Reportable Lists

Between 1992 and 2012, fifteen conditions were added to the nationally notifiable conditions list; these conditions and their years of addition are listed in Table 10. For the purposes of this analysis, the non-communicable/infectious conditions (elevated blood lead, acute pesticide injury or illness, silicosis and cancer) and waterborne outbreaks were excluded, as data about the state patterns of addition to their respective reportable lists was unavailable.

National reporting data were available starting the year of addition to the NNC list; data about state reporting requirements prior to the NNC addition were not available. As a result, it was not possible to differentiate states that implemented condition reporting in the year of the NNC addition from those that required reporting prior to the NNC addition.

The time difference between the addition of a condition to the nationally notifiable conditions list and the addition to the state reportable list ranged from zero to fourteen years. A majority of states made reportable a newly-added nationally notifiable condition for nine of the ten conditions evaluated within 18 months. Babesiosis was the only exception, and was made reportable in 48% of states within 18 months. The results for all conditions are presented in Table 11.

The majority of states that made the condition reportable as of 2015 did so during the year it was added to the NNC list, and 82% of states that chose to add it did so within the first 18 months after the condition was added to the NNC list. The distributions of the times until state addition are provided in Figure 8 through Figure 16.

Question three one summary

A majority of states that added nationally notifiable conditions to their reportable conditions list within 18 months for all ten conditions evaluated. Additionally, nine of ten conditions were made reportable within a majority of all states within 18 months; the tenth condition was made reportable in 48% of states within 18 months. The null hypothesis, that the majority of state-level public health jurisdictions do not add conditions to their list of statereportable conditions within 18 months after they have been added to the list of nationally notifiable conditions, is rejected.

Question Four: Compliance with National Reporting Recommendations

Elevated blood lead

Only three states, Hawaii, South Dakota and West Virginia, do not mandate the reporting of elevated blood lead levels. Of the 49 states that do mandate it, 28 (57%) require reporting of laboratory results in a manner consistent with the position statement making it nationally notifiable in 2010 (Stanbury, 2009), which recommends that any blood lead testing result, regardless of finding, be reported to the health department. The remaining 21 states (43%) require some form of narrower reporting than the national recommendation. The differences in reporting requirements are presented in Table 12.

All 49 states that require reporting of elevated blood lead levels require that clinicians and laboratories report. Additionally, 48 of 49 (98%) states mandate reporting by reporters other than clinicians and laboratories (beyond the national recommendation). Five states (10%) require reporting only by one of the entities explicitly listed in the national recommendation (hospitals, veterinarians, or pharmacies), nine (18%) require reporting only by entities other than those explicitly listed, and 37 (76%) require reporting by both explicitly-listed and non-listed entities.

Only one state, Georgia, has required reporting by entities that match the national recommendation. Georgia also requires the reporting of all blood lead tests in all ages, making it the only state that fully complies with the national recommendation.

Influenza-associated pediatric mortality

Forty-eight states (Table 13) mandated the reporting of pediatric influenza mortality in some form. A majority of states, 27 (56%), specifically required the reporting of pediatric influenza mortality. Twelve states (25%) required influenza mortality reporting of a larger age group. Only 1 state (2%) required that reporting in a narrower age group. Eight states (17%) required the reporting of any influenza disease across all age groups, and this presumably included the reporting of pediatric influenza-associated mortality.

It was not possible to determine if the criteria used by states to require reporting followed the national recommendations (Gensheimer &Fowlkes 2009) on pediatric influenza-associated mortality, as no state listed specific requirements for clinical or laboratory criteria that necessitated reporting of the condition.

Consistent with national recommendations, all states required reporting of pediatric influenza mortality by laboratories and clinicians. Forty-seven of 48 states (98%) required reporting by other entities, consistent with recommendations. Only four states (8%) matched the explicit recommendation of reporting by hospitals, pharmacists or veterinarians. Table 14 provides the state reporting requirements by additional reporters.

Shiga toxin-producing Escherichia coli

Some form of Shiga toxin-producing *Escherichia coli* (STEC) was reportable in all 52 state-level jurisdictions in 2015. Two states (4%) required reporting of *Escherichia coli* O157:H7, a subset of the broader nationally notifiable condition (Dunn & Marder 2013). One
state (2%) required the reporting of the broader category of *Escherichia coli*. The national recommendation included the reporting of persons diagnosed with post-diarrheal hemolytic uremic syndrome; 50 of 52 (96%) state-level jurisdictions mandated reporting of this condition. Additionally the national recommendation included the reporting of persons who have a positive culture for of *Escherichia coli* O157:H7; 30 states (58%) had such a requirement.

The national recommendation included reporting by clinicians, laboratories and other entities (poison control centers, hospitals, veterinarians, and pharmacists). Five states (10%) fully followed this recommendation. Table 15 provides the state reporting requirements by additional reporters.

Tuberculosis

Tuberculosis (TB) was reportable in all 52 state-level jurisdictions in 2015. As presented in Table 16, states took different approaches to TB reporting. Eight states (15%) required the reporting of latent TB infection in addition to active TB cases. Latent TB infection was not recommended to be part of states reporting requirements in the national recommendations (Montero, Hull, Lynch, & Parrish 2009). Also as described in Table 16 are TB-specific reporting requirements for pharmacists, which were required in 13 states (25%).

The national recommendation includes reporting by clinicians, laboratories and other entities (poison control centers, hospitals, veterinarians, and pharmacists). Five states (10%) fully followed this recommendation. Table 17 provides the state reporting requirements by additional reporters, which is identical to the requirements for Shiga-toxin producing *Escherichia coli*. *Question four summary*

There was little consistency between the states or the conditions evaluated for this research question. Some states had reporting requirements beyond the national

recommendations, and others had a more restricted set of requirements than the national recommendations. As such, the null hypothesis that reporting jurisdictions mandate the reporting of conditions on the nationally notifiable conditions list utilizing the same reporting criteria as in the recommendation was rejected.

Summary

State reporting practices varied widely in terms of what was reportable, who was required to report, and the timeframe in which the report must be submitted, supporting the null hypothesis that all state-level public health jurisdictions do not mandate the reporting of all conditions in 2015.

Two state-specific factors associated with a higher number of nationally notifiable conditions being reportable in a state were identified, rejecting the null hypothesis that no statespecific factors are associated with a state including a greater than median number of 2015 nationally notifiable conditions on their respective state's 2015 reportable conditions.

No condition-specific factors were associated with a condition being including on a greater than median number of 2015 state reportable conditions lists, supporting the null hypothesis that one or more condition-specific factors are associated with a condition being including on a greater than median number of 2015 state reportable conditions lists.

A majority of states add nationally notifiable conditions to their reportable conditions list within 18 months for all ten conditions evaluated rejecting the null hypothesis that state-level public health jurisdictions do not add conditions to their list of state-reportable conditions within 18 months after they have been added to the list of nationally notifiable conditions, is rejected.

Finally, states were inconsistent in their implementation of the national reporting recommendations, rejecting the null hypothesis that reporting jurisdictions mandate the reporting

of conditions on the nationally notifiable conditions list utilizing the same criteria set forth in national recommendations.

Chapter 5 – Discussion

Summary of the Study

Differences in state condition reporting have not been previously well described, and the limitations due to these differences are often overlooked both in the popular press and in scientific studies. This study sought to understand these differences and elucidate the factors that lead to the interstate differences in condition reporting. To do so, this study addressed the following questions:

- 1. Do all states require the reporting of all conditions on the 2015 nationally notifiable conditions list?
- 2. What state-specific factors are associated with a state including a large number of these conditions on their reportable conditions list?
- 3. What condition-specific factors are associated with a condition being included on a large number of state reportable conditions lists?
- 4. Do states quickly add conditions to their state reportable lists when they are added to the nationally notifiable conditions list?
- 5. Do states follow national recommendations as to the reporting criteria that are implemented?

Widely-varying implementations of disease reporting between the state-level jurisdictions were identified in this study, and no factors adequately explained these differences. While larger states were more likely to require that a greater number of diseases be reported, there was no linear relationship between population size and the number of reportable conditions.

The most important finding of this study is that the nationally notifiable conditions list is largely a reflection of what is reportable in states and does not really set national priorities.

Adding a condition to the nationally notifiable conditions list does not necessarily lead to states making that condition reportable, and conditions that are reportable in states follow the historical implementation of disease reporting in the state and not national recommendations.

The individual state differences are important to consider when evaluating national disease statistics, as differences in how the data are collected can lead to widely varying reported incidence, even if states have the same true incidence. The fact that such differences exist despite the existence of national disease reporting recommendations creates a large hurdle to overcome to make automated disease reporting from electronic health records a reality.

In general, individual state-level health departments have implemented widely varying approaches to all aspects of the mandatory reporting of disease within their jurisdictions. The reportable conditions, the reporter types, and the timeframes in which reports were required to be submitted differed considerably. With the exception of Nevada, state health department websites were up to date and generally provided the information clinicians needed to report a condition.

States did not provide the codes needed to implement the automated reporting of disease from electronic health records or through electronic laboratory reporting on their websites. Only one state, Missouri, provided the ICD-9 and ICD-10 codes for a majority (but not all) of their reportable conditions. This is a severe limitation of NNDSS, as these codes are necessary to ensure prompt and complete reporting of laboratory results and diagnoses.

A proposed solution to the lack of codes was the creation of the "Reportable Conditions Mapping Table", a list of Logical Observation Identifiers Names and Codes (LOINC) codes used to classify laboratory results (Centers for Disease Control and Prevention, 2012). This solution has major limitations, as it is described as standardizing "reportable lab result reporting to public health", but only contains nationally notifiable conditions and does not include the many non-

nationally notifiable conditions reportable in states that were identified in this study. As the legal foundation of disease reporting is based in state laws, the list is not usable without all state-required conditions, and its utility is limited to use for electronic laboratory reporting as it does not contain reportable diagnosis codes.

An added layer of complexity in developing an ontology for condition reporting is that 11% of conditions reportable to state-level health departments are done so under a broader parent category. In order for the ontology to accurately reflect the reporting requirement of the states, it would have to include the relationships between conditions and the broader reporting category by which they are reported. This may be straightforward for a condition such as acute hepatitis B being reported under the broad category of hepatitis B, but this ontology would be very complex if had it to include broad categories such as occupational disease or unusual occurrences of illness.

The 28 different reporting timeframes used in states are an unnecessary complexity due to having no national standards for general condition reporting. The purpose of the timeframes can be inferred from the notification timeframes used by CDC: immediate, urgent, and routine (plus a special category for cancer reporting). This is consistent with the finding that states use, on average, four different reporting timeframes.

Of even greater complexity are the 72 different reporter types that are required to report conditions in different states. Many of these reporter types are non-medical, such as food facilities, camps or parole officers, and would be relying on the clinical or laboratory diagnosis of another required reporter. Similarly, many of the required medial reporter types would not be involved in a primary diagnosis, such as a contact lens distributor, dietitian or occupational therapist. Many of these reporter types were included in state regulations because the regulations

broadly require medical professionals licensed in the state under the purview of a particular licensing authority to report.

Over half of the identified reporter types are only required to report in one or two states, which calls into question the utility of including these reporter types. This is consistent with the standard template for adding a condition to the nationally notifiable conditions list which specifically mentions only six reporter types as sources for case ascertainment: clinicians, laboratories, and other entities (e.g. hospitals, veterinarians, pharmacies, and poison control centers) (Council of State and Territorial Epidemiologists 2015).

There are several approaches to resolving the problem of interstate differences in disease reporting. Conceptually, the simplest approach is to create a federal mandate for disease reporting to be followed by all states. This is not feasible, as it would require a constitutional amendment to give this power to the federal government. However, this did not prevent (ultimately unsuccessful) attempts to put the system under federal control. Under the guise of bioterrorism preparedness, Nebraska senator Chuck Hagel introduced the National Reportable Conditions Act in 2006, which would have created a second list of nationally notifiable conditions and established the National Reportable Conditions System, a system to report these conditions to the Department of Homeland Security (S. 3898, 2006). The bill was not passed out of committee. It was reintroduced two years later as the National Integrated Public Health Surveillance Systems and Reportable Conditions Act, which removed the reporting provisions and replaced them with a request for additional funding of the existing system (S. 3476, 2008). As with the previous bill, it did not pass out of committee, indicating that congress was not interested in taking up this issue.

A second approach would be for the states to voluntarily agree to use the same list of reportable conditions, reporter types and timeframes. This approach would not face the same constitutional issues as a top-down, federally-mandated approach, as it would be under the control of the states. In order to be successful, this project would require a governance structure, funding, and a commitment from states to not continue to create their own version of the central system; this would be similar to the challenges of managing an open-source software development effort. However, states have always had this option and have not chosen to standardize any parts of the reporting process other than case definitions, as is evident from this study. The result of this approach is the dysfunctional system currently in place, and it is unlikely to change.

The approach most likely to succeed would the approach the federal government has taken to implementing issues in transportation, namely a consistent blood alcohol content level for drunk driving across all states. States were not mandated by congress to establish a .08 blood alcohol content level for drunk driving; however, congress used the leverage of withholding federal highway funding as a way to coerce states to follow their wishes. This action was found to be a constitutional use of the commerce clause of the United States Constitution in South Dakota v. Dole (1987).

This approach could be particularly effective in public health, where federal funding makes up a majority of most states' public health budget. In fiscal year 2013, states spent \$11.1 billion to fund public health activities, while federal funding distributed to states from CDC and the Health Resources and Services Administration totaled \$12.8 billion (Levi & Segal, 2014). Funding is provided in the form of cooperative agreements (non-competitive, often population-

based allotments) and competitive grants, and could be used as leverage to push states toward adopting national standards.

The commerce clause has often been used to allow the involvement of the federal government in issues which for which it has not been given explicit power in the United States Constitution. Whether withholding cooperative funding is allowed under the commerce clause would be an issue for constitutional lawyers to decide, but there should be no issue in the inclusion of such a requirement in grants issued by the CDC, as the numerous requirements of existing grants have not been acceptable to states.

In order to implement a comprehensive change to standardize the system across the states, I propose a complete overhaul of state disease reporting and national notification. There are several steps to this proposal:

- 1. Establish an independent organization to manage the system and serve as the national standards developing organization (SDO).
- 2. Develop the standards which will be implemented in all reporting jurisdictions, at the state, local and territorial levels.
- 3. Modify state laws to incorporate the newly-developed standards.
- 4. Require that states follow the standards in order to be eligible for CDC grant funding.

The first step, the establishment of the SDO, is necessary as there is no organization that represents all partners on an equal basis. The focus of the project, and disease reporting in most discussions, is at the state level. However, state laws often make the local health departments responsible for the management of the system and place the state in the role of simply aggregating data from the local health departments. This is the case in Nevada, where county health departments are given broad authority to prevent and control disease (Nevada Revised

Statutes 439: Administration of Public Health, 2013), and are required simply to inform the state's Chief Medical Officer of the number of identified cases or suspected cases on a weekly basis (Nevada Revised Statutes 441a.170: Weekly reports to Chief Medical Officer, 2013). Also, as described earlier, some local health departments have the legal authority to mandate the reporting of conditions of local concern.

In order to establish an SDO that equally represents these different sectors of the diseasereporting continuum, a new organization would have to be created, as existing organizations only represent individual levels of disease reporting, such as local health departments or state health departments. It would also be important to include representatives of clinicians, laboratories and other reporter types, as the practical concerns of disease reporting and the burden it places on reporters would also have to be considered.

The major barrier to the first step would be the funding of such an organization. However, if this organization is the result of a federal push for standardization, the CDC would ultimately be responsible for the financial support of the organization.

The second step in implementing a solution would be the development of a formal standard for disease reporting. A form of this process already exists through CSTE position statements and the development of disease-specific standards at CDC. These process would be merged into a community-driven process through the SDO, and would result in a clear, comprehensive standard that could be applied at all levels of disease reporting. It would define which conditions are nationally notifiable, the case definitions for all conditions of interest to public health, the reporter types required to submit reports, the timeframes in which they must be submitted, the data that must be included in the initial report submission, and the technical process that is used for condition report submission. Additionally, the data elements included in

the reporting and notification of the condition would be included, which, unlike the current process, would allow for the participation of the groups that generate the data (e.g., clinicians and laboratories) and those that collect the data (e.g., county and city health department).

The major barrier to the second step would be differing opinions on what should be included in the standard. This is not an uncommon problem for any SDO, and the SDO can be structured to deal with these issues. This SDO could be modeled after other community-based SDOs such as Health Level 7 (HL7), which develops standards through a democratic process of ballot proposals and member voting.

The third step in the process would the modification of state, territorial, and local regulations to use the newly-developed national standards. While this process is easy to describe conceptually, it will be difficult to implement as it requires understanding the laws of each reporting jurisdiction in the country. This process will be different for each reporting jurisdiction; in some cases, these changes will require legislative action, and in others it will be a rulemaking process that falls under the state health department. As a result, while states can learn from the successes and failures of other states, a single, effective approach cannot be develop that will work across all jurisdictions.

There are two barriers to this step of the process. First, there are fiscal challenges in hiring additional staff to evaluate existing legislation and craft appropriate modification of the state laws. CDC could provide direct financial support to states as part of existing funding streams such as the Public Health Emergency Preparedness cooperative agreement or the Epidemiology and Laboratory Capacity grant program. This could overcome state objections to the expense of such a project. The second barrier is political, as this requires working through a political process to change legislation, and varies by state. The CDC could play a role in assisting

health departments, helping to prepare state health officials for legislative testimony or testifying directly to legislative committees on the need for such a system.

The final step in implementation is requiring that states follow the national standard to be eligible for federal public health funding. While it would be unethical to withhold funding to pay for the vaccination of low-income children, it would be reasonable to withhold funding for surveillance and investigation activities if states do not choose to follow the national standards.

The barrier to this step would be political, for example, pressure on CDC from a highlyranking member of the Senate finance committee from a state that does not want to follow the national standard. This political pushback would be unlikely to occur at this point, as the states would have been involved in the process of developing the standards and have been supported by CDC and other states in the modification of their regulations.

In summary, the development and implementation of a national reporting standard is feasible through a well-planned, inclusive, financially-supported process. If states are given time to comply and the support to do so, a national standard of disease reporting could become a reality. The requirement that states use national standards in their reporting process to be eligible for CDC grants would provide the incentive to participate in the process, and would ensure that all states do so in a reasonable timeframe.

Research Question One Discussion

Despite the recommendation in the position statement that made each condition nationally notifiable by a majority vote of states that "all States and Territories enact laws (statue or rule/regulation as appropriate) to make this disease or condition reportable in their jurisdiction" (Council of State and Territorial Epidemiologists, 2015), some states have chosen not to follow this advice for a majority of nationally notifiable conditions.

Only 30% of all conditions were explicitly reportable in all states, and 43% of nationally notifiable conditions are reportable in all states if the other categories of disease reporting (broader and narrower) were included. Only two-thirds of conditions were reportable in at least 90% of states, and only one state was found to require that all NNCs be reported. The findings of this study are consistent with the evaluation of the 2008 State Reportable Conditions Assessment (SRCA) that found that two-thirds of nationally notifiable conditions were explicitly reportable in over 90% of states (Jajosky et al. 2011).

Incorrect reporting of which diseases are reportable to the CDC by listing a condition as reportable when it is not (through the SRCA and by submitting disease notifications weekly) presents an issue affecting national disease rates. For example, New Mexico routinely reports pertussis cases to CDC through the NNDSS and listed it as being reportable on the SRCA despite not being listed as a reportable disease in their disease charts or state regulations. If it is required to be reported because it is a "condition dangerous to public health or safety" (New Mexico Administrative Code 7.4.3.7, 2012) but is not dangerous enough to include as explicitly reportable despite it occurring every year and requiring a public health response, then it raises the question of why New Mexico conducts surveillance on the condition at all. The result of states identifying a condition as reportable when it is not is an underestimation of the national rates, as the states contribute fully to the population denominator but partially or not at all to the numerator (number of cases).

Differences in the implementation of condition reporting at the state and local level raise a question about the process of making a condition nationally notifiable: do states make a disease reportable because it is nationally notifiable, or do states make it nationally notifiable because it is reportable in a majority of states?

For the conditions evaluated in this analysis, an average of 34 states required the reporting of a condition in the year it was added to the nationally notifiable conditions list. An average of 3 states added the condition to the state's reportable condition list the year after it was added, and an average of 8 states added it at a later time. This would indicate that the state reporting practices drive the inclusion of conditions on the NNC list, rather than the NNC list driving state reporting practices.

Examples of this can be found in the position statements that have added conditions to the NNC list. In adding giardiasis to the NNC list, Gibson and Ball noted that "Less than 10 states will need to establish Giardiasis as a reportable condition" (2001). When campylobacteriosis was added to the list, it was noted that 49 states and territories already mandated reporting (Bradlek, DeMaria Jr, & Geissler, 2014). The addition of cancer to the NNC list was justified in part because "all states have a cancer registry that is statewide and population-based" (Hylton & Huang, 2009). Nineteen states reported an explicit reporting requirement and sixteen states reported an implicit requirement on the 2010 SRCA (Council of State and Territorial Epidemiologists, 2011); 24 states notified CDC of cases of babesiosis the first year it was nationally notifiable.

There is no official position by the nation's epidemiologists that states that the state rules drive the placement of a condition on the NNC list. In 2008 CSTE passed a position statement that required that a condition be reportable in half the states or states comprising 50% or more of the United States population before it could be added to the NNC list (Engel 2008). However, this requirement was removed two years later over concerns about the inability to add emergent conditions to the list (Rolfs & Smith 2010). Based on this series of events, it can be inferred that adding emergent conditions to the NNC list can drive states to adopt reporting, but routine

conditions (the bulk of those added to the nationally notifiable list) are added to the nationally notifiable conditions list only when they are reportable in a number of states. No emergent conditions have been added to the NNC list since 2010, so this cannot be evaluated.

State reporting practices driving the nationally notifiable conditions list is consistent with supporting the null hypothesis that all state-level public health jurisdictions do not mandate the reporting of all conditions on the 2015 nationally notifiable conditions list. In general, if states did not require that a particular condition be reported before it was added to the nationally notifiable conditions list, it is unlikely that they will take swift action to make it reportable once it is added to the national list.

Research question two, part one: what state-specific factors, if any, are associated with a state including a greater than median number of 2015 nationally notifiable conditions on their respective state's 2015 reportable conditions list?

Research Question Two, Part One Discussion

Total CDC funding and state population were both identified as having a statistically significant association with the number of nationally notifiable conditions reportable in the states when grouped into a dichotomous high/low category and led to a rejection of the null hypothesis that no factors were associated with a state including a greater than median number of 2015 nationally notifiable conditions on their respective state's 2015 reportable conditions list. However, neither factor was statistically significant when evaluated for a linear relationship between the level of funding and the number of reportable conditions. Additionally, both factors were strongly correlated with each other; unsurprisingly, states with a large population receive large amounts of CDC funding.

This finding may be due to the way in which states are funded for public health programs by the CDC. Many CDC sources of funding are distributed based on state population with larger states receiving more money. The funding would allow larger states to hire staff to develop specific surveillance programs and work on specific projects, including surveillance for particular conditions. These additional programs may drive state decisions to add nationally notifiable conditions to their reportable conditions list. This evaluation was beyond the scope of this project, and would require a detailed analysis of CDC grant funding to each state over time as well as the grant deliverables for multiple grant-funded programs.

Research Question Two, Part Two Discussion

No condition-specific factors were identified as being associated with being included on state reportable conditions list. This is not surprising, given the identification in question one of state reportable lists driving the nationally notifiable list. Four of the factors that were evaluated are classifications that are used by CDC, and if states are driving what is nationally notifiable, those classifications would not play a role in state decisions to make a disease reportable. A number of the conditions that are vaccine preventable (the fifth factor evaluated) have been on the nationally notifiable conditions list since its inception in 1951 (Dauer, 1952) and are reportable in all states. Varicella is the only exception, and was reportable in over 80% of states. The high level of reporting for vaccine-preventable conditions makes a statistical comparison impossible, as there is no group against which comparisons could be made.

Research Question Three Discussion

Although it was found that a majority of states do add conditions to their reportable lists within 18 months of their addition to the NNC list, this may be misleading. Data are available about which conditions were reportable in each state starting the year of addition to the NNC, but

state reporting requirements prior to those years could not be analyzed. Given that state reportable condition requirements appear to drive the NNC list additions, it is likely that the states were not adding the condition quickly after it was added to the list, but that they were reporting data to CDC for conditions that were already reportable in the state.

At first glance, babesiosis appears to be an outlier, with only 24 states requiring the reporting of the condition in 2011, the year it was added. As the disease is transmitted by the same tick that causes Lyme disease, the states that routinely identify cases of Lyme disease were the states that made it reportable. Of the 15 states with the highest reported cases of Lyme disease in 2012, 13 required the reporting of babesiosis (Adams et. al, 2014). babesiosis can be thought of as an extension of Lyme disease reporting, and is consistent with the idea that state reportable conditions drive the nationally notifiable conditions list. As described earlier, babesiosis was explicitly reportable in nineteen states on the 2010 SRCA, which was conducted before babesiosis was added to the NNC list (Council of State and Territorial Epidemiologists, 2011).

Research Question Four Discussion

For three of the four conditions evaluated, elevated blood lead, influenza-associated pediatric mortality and Shiga toxin-producing *Escherichia coli*, laboratory testing is a necessary part of disease reporting (i.e. a report cannot be filed without laboratory evidence). As a result, including a number of additional reporting entities would likely not increase the reporting rate of disease, as the laboratories (which are required to report in all 52 state-level jurisdictions) are the true source of information. Point-of-care testing for blood lead is the one exception, although clinicians performing such a test are required to report as if they were a laboratory in many states.

For tuberculosis, laboratory testing is necessary for confirmation and classification of the case, but states typically require that the condition be reported based on clinical presentation alone, as laboratory testing can take weeks to months to complete. Reporting by pharmacists of patients who have been prescribed antibiotics typically used for the treatment of tuberculosis may increase early case finding and help public health officials take early action, but will not affect overall disease reporting, as the laboratory will eventually report positive cases.

The diversity of disease reporting requirements in states, coupled with minimal information contained in laboratory reporting requirements in each state, made the analysis of this research question difficult. However, this is consistent with states driving additions to the nationally notifiable conditions list. If states have already made the disease reportable when it is added to the nationally notifiable conditions list, there is little incentive to modify the state reporting laws to match recommendations that are not legally binding.

Implications

The most important implication of this study is that the data presented as describing the incidence or prevalence of disease in the United States is collected in an inconsistent manner to the extent that it may be unreliable or subject to manipulation by states, especially if funding is tied to the incidence or prevalence of disease. If data are collected in an inconsistent manner from state to state, the results will not be comparable even if identical case definitions are used. The case definition can be thought of as a filter, only allowing certain types of cases to flow through. However, if the volume of reports being filtered in two states differs because the laws of one state result in a greater percentage of cases being reported, one state would have a higher rate of reported disease even with the same underlying true rate of disease.

Another implication of this study derives from the identification that states are largely driving what is placed in the nationally notifiable conditions list rather than being driven to make nationally notifiable conditions reportable within their jurisdictions. As a result, the national standards are based on what was developed in an isolated, parallel fashion in multiple states. This also makes states less likely to change their reporting rules to match a national standard. Any attempts to standardize disease reporting across the states would be extraordinarily difficult, as there is no lead agency that the states would follow.

These intrastate differences could create significant barriers to the electronic reporting of disease from electronic health records (EHR), as systems would have to be developed that were unique to each reporting jurisdiction. EHR vendors are likely to be unwilling to customize the disease reporting to match the peculiarities of disease reporting in the over 3,000 local health departments in the United States. The result will either be an unwillingness to provide any electronic reporting of disease or forcing the health departments to use a standard, vendor-developed system that does not meet the needs of the health departments.

The findings of this study also have implications for the Reportable Conditions Knowledge Management System (RCKMS), which has been endeavoring to create a central electronic database of reporting requirements that is usable both by humans and machines (Altamore, Conn, Staes, & McGarvey, 2013). Most recently, the RCKMS has piloted the development of a set of standardized reporting criteria among several states and local health departments. While the development of such a standard would be beneficial to public health, it would require states to change their laws in order to implement it. While Altamore, Smithee, Vahora, & Arnold concluded that "Providing -- and maintaining -- a single, comprehensive, authoritative, real-time portal to reportable conditions information presents substantial

challenges, to which the public health community" (2015), they focused only on the technical aspects of such a project. The actual implementation of such a system, even if the technical aspects are resolved, would be much more complex due to the fact that states are driving the national standards while simultaneously failing to follow those standards.

Limitations

This study focused on the 52 state-level reporting jurisdictions and not the over 3,000 local health departments. Large counties and cities such as Los Angeles, Las Vegas (Clark County) and Chicago have considerable public health capacity and may provide better-designed or more complete reporting information to clinicians and laboratories required to provide the reports. The evaluation of local disease reporting processes and requirements was beyond the scope of this study.

The most significant limitation in this study was the limited information provided in the reporting regulations for each state. While states included the names of conditions that were reportable, they generally did not provide any additional criteria that necessitated a report being submitted to the local or state health department.

This issue is rooted in the way state regulations are written, as they are generally crafted to broadly require the reporting of disease without limitation. For example, Nevada statute required that health care providers report a condition if it a healthcare provider determines that the person had a reportable condition based on "Clinical signs and symptoms consistent with the communicable disease" (Nevada Administrative Code Chapter 441A.180, 2011). No further description of the clinical signs or symptoms was given in the regulations, leaving it up to the discretion of the clinican.

The issue of interpretation of what is reportable by a clinician is not a new issue, as it was a concern with the first clinician reporting system developed in in 1875. The solution today is no different today than was described 140 years ago:

For this diversity there is no radical remedy. It is the source of a considerable margin of error in the registration of mortality, affecting the causes of death; it is the possible origin of a still wider range of uncertainty in the results of any scheme for registering diseases which do not afford, in their fatal termination, an additional indication for diagnosis. Our chief safe-guard is again to be found in the known skill and reputation of the observers. (State Board of Health of Massachusetts, 1875, p. 481)

The same issue of limited explanation of what is reportable exists for laboratories, as states do not provide a list of laboratory tests that require submission to the health department. In Nevada, laboratories must report to the health department findings "in which a test or examination of any specimen derived from the human body yields evidence suggesting the presence of a communicable disease, a causative agent of a communicable disease or an immune response to a causative agent of a communicable disease" (Nevada Administrative Code Chapter 441A.235, 2011). All changes to disease reporting regulations must go through a process that involves drafting by the Legislative Council Bureau, public hearings, approval by the State Board of Health, and finally approval by the a committee comprised of the governor, secretary of state and the attorney general. The length of this process makes it impractical to list specific laboratory tests in regulation, as newly-approved tests would potentially not be added for years.

An additional limitation is the variation between states in how reportable conditions are presented to clinicians, laboratories, and other entities required to submit reports. The lists typically presented to reporters do not contain all condition reporting requirements listed in state

statute and regulations. They are not presented in a consistent format and may use multiple terms to describe conditions (for example, using the term "leprosy" to describe Hansen's disease).

Another limitation is the lack of data on state reporting requirements in the years prior to a condition's addition to the nationally notifiable conditions list. If state reporting practices are driving the additions to the list, it would be possible to see this in the state reporting requirements. Data on the history of each state's reporting practices and changes to the list may be available for recent years, but identifying those changes before the internet was used to distribute the lists would require identifying and reviewing printed materials from each health department, assuming such materials still existed.

A final limitation is the inclusion on state reportable lists of the category of "unusual disease" reporting. While this category serves a necessary purpose of mandating the reporting of newly emerging or rare conditions in a jurisdiction, it is often used as a catch-all category for anything that has not been added to the state's list. The use of such a broad catch-all category to mandate the reporting of nationally notifiable conditions by clinicians rather than specifically listing the known reportable conditions would result in misleading results for this study, but more importantly, potential underreporting on the part of laboratories and clinical providers.

Future research

There has been little research conducted in this area, with most focusing on improving the completeness and timeliness of disease reporting from laboratories and clinicians to the local health department. Future research can be grouped into two broad areas: further explorations of the Nationally Notifiable Diseases Surveillance System and development of standard methods of disease reporting and notifications.

While additional study of the Nationally Notifiable Diseases Surveillance System could explain particular aspects of system differences in more depth, it is unlikely to provide a practical benefit, as additional cataloging of the dysfunction and variability in the NNDSS would do little to resolve those issues. Of benefit would be an in-depth analysis of the role of implicit report disease reporting in states, covering both the general categories such as vector-borne disease and the broad public health reporting mandate of unusual illnesses.

This research would serve two purposes. First, it would explain how states use broad categories to potentially simplify the disease reporting process for humans and highlight the impact of such simplification on the development of electronic reporting systems. It would also better describe the types of information that would need to be included in a centralized system for disease reporting (such as the Reportable Conditions Knowledge Management System) in order to make algorithmic decisions about the reporting of a potential case to public health.

Second, it would describe how the states are using the category of unusual illness within their jurisdiction. While such a category is necessary so that public health officials can identify and respond to newly emerging disease threats, it can be misused in order to make routine issues reportable within the state (as was the example of Pertussis in New Mexico described earlier). This research would have implications for the political factors involved in the implementation of a centralized reporting system.

A second area of research is in the development of systems that could be used to standardize disease reporting across all jurisdictions. While some study has been conducted in this area, it has been generally limited to specific implementations of a system such as the Reportable Conditions Knowledge Management System, rather than in a deep understanding of the factors, both technical and political, on which the success of the system would hinge.

Conclusion

Data collected through the Nationally Notifiable Diseases Surveillance System is used for a variety of practical applications throughout public health and is often treated as if it is a standardized system with reliable, comparable data across all states. In reality, differences between state reporting processes make it difficult to reliably compare data across states, as each states is in essence using different inclusion criteria for each disease. State reporting requirements varied widely on what is reportable, which entities must report, and the timeframes in which a condition must be reported. This variability is not reflected in national statistics, where state differences are ignored and conditions are treated as if they are the same from state to state.

This variability is driven by the process that creates the nationally notifiable conditions list, as conditions are typically added to the list only after a large number of states have already chosen to make the condition reportable. As there is no national standard to follow during the development of the state reporting requirements, states develop their reporting requirements based on the nuances of the existing individual state reporting process and regulations. The end result is that when a condition is added to the nationally notifiable conditions list, it is done so as a hybrid of the many state reporting requirements (which do not reflect the actual practices of any one state), and states typically do not change their reporting requirements to match this new standard.

While the Nationally Notifiable Diseases Surveillance System provides flexibility for the states to only include conditions that are of importance to the state or are within the capacity of the state to investigate and respond to, it also allows states to develop reporting requirements that vary widely from other states. This variability must be eliminated if a standardized reporting

process is to be adopted to allow for electronic reporting of disease to public health authorities in the United States.



Figure 1. United States Department of Health and Human Services human subject regulations decision chart 1, emphasis added (US Department of Health and Human Services, 2004)



Figure 2. Years since state reportable list was updated (as of June 1, 2015) (N=52)



Figure 3. Distribution of the number of states requiring the reporting of Nationally Notifiable Conditions (N=52)



Figure 4. Number of states requiring disease reporting within a given timeframe (N=52)



Figure 5. Number of states requiring the reporting of a condition not on the nationally notifiable conditions list (N=52)



Figure 6. The distribution of states requiring a number of non-NNCs to be reported (N=52)



Figure 7. Distribution of the number of conditions required to be reported in states (N=52)



Figure 8. Years from addition of babesiosis to the NNC and addition to state reportable lists (N=33)



Figure 9. Years from addition of cyclosporiasis to the NNC and addition to state reportable lists (N=44)



Figure 10. Years from addition of *Escherichia coli* O157:H7 to the NNC and addition to state reportable lists (N=52)



Figure 11. Years from addition of giardiasis to the NNC and addition to state reportable lists (N=48)


Figure 12. Years from addition of Q fever to the NNC and addition to state reportable lists (N=50)



Figure 13. Years from addition of *Streptococcus pneumoniae*, invasive, less than 5 years of age to the NNC and addition to state reportable lists (N=46)



Figure 14. Years from addition of *Streptococcus pneumoniae*, invasive to the NNC and addition to state reportable lists (N=44)



Figure 15. Years from addition of varicella, invasive to the NNC and addition to state reportable lists (N=42)



Figure 16. Years from addition of vibriosis, invasive to the NNC and addition to state reportable lists (N=44)

Appendix B: Tables

State	Explicitly Bonortable	Broadly Benertable	Narrowly Bonortable	Any Deportable	Not Bonortable
Alahama	<u>63</u>		<u>Reportable</u>	67	13
Alaska	54	14	2	70	10
Arizona	64	8	3	75	5
Arkansas	63	13	1	77	3
California	65	9	2	76	4
Colorado	49	11	4	64	16
Connecticut	61	4	3	68	12
Delaware	65	11	1	77	3
District of Columbia	53	12	5	70	10
Florida	65	9	2	76	4
Georgia	58	11	3	72	8
Hawaii	56	6	3	65	15
Idaho	48	11	4	63	17
Illinois	60	8	3	71	9
Indiana	61	5	3	69	11
Iowa	53	12	1	66	14
Kansas	59	9	3	71	9
Kentucky	56	5	0	61	19
Louisiana	73	б	1	80	0
Maine	64	3	3	70	10
Maryland	64	9	3	76	4
Massachusetts	60	14	2	76	4
Michigan	70	6	0	76	4
Minnesota	60	15	0	75	5
Mississippi	58	6	3	67	13
Missouri	73	0	4	77	3
Montana	67	7	1	75	5
Nebraska	64	7	3	74	6
Nevada	57	13	3	73	7
New Hampshire	55	9	1	65	15
New Jersey	69	2	3	74	6
New Mexico	64	5	3	72	8
New York	64	5	3	72	8
New York City	64	5	3	72	8
North Carolina	63	4	3	70	10
North Dakota	52	17	1	70	10
Ohio	67	8	0	75	5

Table 1. Number of conditions reportable in each state by reporting type (N=80)

0111	 	6	4	C 1	10
Oklahoma	54	6	4	64	16
Oregon	56	11	0	67	13
Pennsylvania	54	14	2	70	10
Rhode Island	59	10	5	74	6
South Carolina	64	7	3	74	6
South Dakota	67	3	3	73	7
Tennessee	66	4	4	74	6
Texas	65	5	1	71	9
Utah	72	5	1	78	2
Vermont	60	13	0	73	7
Virginia	67	4	4	75	5
Washington	60	3	4	67	13
West Virginia	69	1	3	73	7
Wisconsin	62	13	0	75	5
Wyoming	60	13	3	76	4

Nationally Notifiable Explicitly Broadly Narrowly Any Not Condition Reportable Reportable Reportable Reportable Reportable Anaplasmosis Anthrax Arboviral diseases Babesiosis Botulism Brucellosis Campylobacteriosis Cancer Carbon monoxide poisoning Chancroid Chlamvdia trachomatis infection Cholera Coccidioidomycosis Congenital syphilis Cryptosporidiosis Cyclosporiasis Dengue virus infections Diphtheria Ehrlichiosis Foodborne disease outbreak Giardiasis Gonorrhea Haemophilus influenzae, invasive disease Hansen's disease Hantavirus infection Hantavirus pulmonary syndrome Hepatitis A, acute Hepatitis B, acute Hepatitis B, chronic Hepatitis B, perinatal infection Hepatitis C, acute Hepatitis C, past or present **HIV Infection** HUS, post-diarrheal Influenza pediatric mortality

Table 2. Number of states requiring the reporting of an NNC by reporting requirement type (N=52)

Invasive pneumococcal disease

Lead, elevated blood levels

Legionellosis	52	0	0	52	0
Leptospirosis	35	0	0	35	17
Listeriosis	52	0	0	52	0
Lyme disease	51	0	0	51	1
Malaria	52	0	0	52	0
Measles	52	0	0	52	0
Meningococcal disease	52	0	0	52	0
Mumps	52	0	0	52	0
Novel influenza A virus	33	9	0	42	10
infections Portuggie	51	0	0	51	1
Posticida illness and injury	22	0	0	26	1
acute	22	4	0	20	20
Plague	52	0	0	52	0
Polio, paralytic	51	1	0	52	0
Poliovirus, nonparalytic	22	1	0	23	29
Psittacosis	50	0	0	50	2
Q fever	50	0	0	50	2
Rabies, animal	33	0	0	33	19
Rabies, human	52	0	0	52	0
Rubella	52	0	0	52	0
Rubella, congenital syndrome	44	1	0	45	7
Salmonellosis	52	0	0	52	0
SARS	44	0	0	44	8
Shigellosis	52	0	0	52	0
Silicosis	12	0	3	15	37
Smallpox	50	0	1	51	1
Spotted fever rickettsiosis	12	10	26	48	4
Staphylococcal toxic shock syndrome	19	20	0	39	13
STEC	49	1	2	52	0
Streptococcal toxic shock syndrome	23	19	0	42	10
Syphilis	52	0	0	52	0
Tetanus	52	0	0	52	0
Trichinellosis	48	1	0	49	3
Tuberculosis	52	0	0	52	0
Tularemia	52	0	0	52	0
Typhoid fever	49	3	0	52	0
Varicella	39	0	4	43	9
Varicella deaths	10	33	0	43	9
Vibriosis	45	0	0	45	7
Viral hemorrhagic fever	40	1	1	42	10
Vancomycin-intermediate Staphylococcus aureus	31	2	0	39	13

Vancomycin-resistant Staphylococcus aureus	42	3	0	45	7
Waterborne disease outbreak	22	29	0	51	1
Yellow fever	46	4	0	50	2

Table 3. Nationally notifiable conditions reportable in all jurisdictions

Category	Conditions
Explicitly reportable	24 conditions: Anthrax, Botulism, Brucellosis, Cancer, Cholera,
in all jurisdictions	Cryptosporidiosis, Diphtheria, Gonorrhea, HIV Infection,
	Legionellosis, Listeriosis, Malaria, Measles, Meningococcal
	disease, Mumps, Plague, Rabies, human, Rubella, Salmonellosis,
	Shigellosis, Syphilis, Tetanus, Tuberculosis, Tularemia
Explicitly reportable	5 conditions: Congenital syphilis, Hepatitis A (acute), Hepatitis
or broadly reportable	B (acute), Polio (paralytic), Typhoid fever
in all jurisdictions	
Explicitly reportable	3 conditions: Arboviral diseases, Chlamydia
or more narrowly	trachomatis infection, Haemophilus influenzae invasive disease
reportable in all	
jurisdictions	
Explicitly reportable	2 conditions: Foodborne disease outbreaks, Shiga toxin-
by any category in all	producing Escherichia coli
jurisdictions	

Table 4. Percent of conditions required to be reported as part of a broader category than the NNC

Nationally Notifiable Condition	Percent	Reportable condition
Varicella deaths	77	Varicella
Hepatitis B, perinatal	63	Hepatitis B
Hemolytic uremic syndrome, post-diarrheal	62	Hemolytic uremic syndrome
Waterborne disease outbreak	57	Disease outbreaks
Hepatitis C, past or present	56	Hepatitis C
Hepatitis B, acute	52	Hepatitis B
Staphylococcal TSS	51	Toxic shock syndrome
Hepatitis B, chronic	51	Hepatitis B
Congenital syphilis	50	Syphilis
Hepatitis C, acute	49	Hepatitis C
Hantavirus pulmonary syndrome	49	Hantavirus
Streptococcal toxic shock syndrome	45	Toxic shock syndrome
Pediatric influenza mortality	44	Influenza
Foodborne disease outbreak	42	Disease outbreaks

Table 5. Difference between percent of population covered by required reporting of an NNC and percent of states requiring the reporting of an NNC (N=52)

	Percent
NNC	Difference
Pesticide Illness and Injury, Acute	+15
Anaplasmosis	+12
Babesiosis	+9
Chancroid	+9
Poliovirus, nonparalytic	+9
Rabies, animal	-10

State Reportable Condition	States
Unusual disease	52 (100%)
AIDS	37 (71%)
Group A Streptococcus	37 (71%)
Outbreaks	37 (71%)
Creutzfeldt-Jakob disease	35 (67%)
Yersiniosis	27 (52%)

Table 6. Non-nationally notifiable conditions reportable in a majority of states (N=52)

Table 7. Required reporting of NNCs removed from the list, 1951-2015 (N=52)

Condition Removed from NNC List	Year Removed	States
Influenza	1951	9 (17%)
Pneumonia	1951	0 (0%)
Murine typhus fever	1994	13 (25%)
Rheumatic fever	1994	8 (15%)
Amebiasis	1995	15 (29%)
Aseptic meningitis	1995	6 (12%)
Encephalitis, post-chickenpox	1995	0 (0%)
Encephalitis, post-mumps	1995	0 (0%)
Encephalitis, post-other	1995	0 (0%)
Encephalitis, primary	1995	20 (38%)
Granuloma inguinale	1995	14 (27%)
Lymphogranuloma venereum	1995	19 (37%)
Hepatitis, non-A, non-B, acute	2002	0 (0%)
Group A Streptococcal infections	2010	37 (71%)

State-specific factor	X ²	p-value
Health ranking	0.321	0.571
Public health funding, total	1.282	0.258
Public health funding, per capita	0.000	1.000
CDC funding, total	1.282	0.258
CDC funding, total, per capita	0.000	1.000
Physicians, per capita	0.321	0.571
Population	1.282	0.258
Population density	0.321	0.571
State area	0.321	0.571
Vaccination rate	1.282	0.258
Educational attainment, high school	0.321	0.571
Educational attainment, bachelors	0.000	1.000
Educational attainment, advanced	0.321	0.571
Emerging Infections Program participant	0.721	0.396

Table 8. Association of state-specific factors with the number of nationally notifiable conditions reportable in a state (N=52)

Table 9. Association between condition-specific factors and the number of states in which the nationally-notifiable condition was reportable (N=52)

Condition-specific factor	Pearson X ²	p-value
Category A agent	1.550	0.213
Vaccine-preventable	0.036	0.850
Notification: immediate, extremely urgent	1.455	0.228
Notification: immediate, urgent	0.091	0.763
Notification: standard	0.887	0.346

Condition	Year Added
Escherichia coli O157:H7	1995
Elevated blood lead	1995
Acute pesticide injury or illness	1996
Silicosis	1996
Cyclosporiasis	1999
Ehrlichiosis/Anaplasmosis	1999
Q Fever	2000
Giardiasis	2002
Varicella	2003
Waterborne outbreaks	2006
Vibriosis	2007
Cancer	2009
Streptococcus pneumonia, invasive, < 5 years of age	2010
Streptococcus pneumonia, invasive, all ages	2010
Babesiosis	2011

Table 10. Conditions added to the NNC between 1992 and 2012

Table 11. Number and percent of NNCs made reportable in states the year of and year after addition to the NNC list (percent calculated of states requiring reporting) (N=52)

	Added in	Added in	Added after
Condition	year 0	year 1	1 year
Babesiosis	24 (73%)	1 (3%)	8 (24%)
Cyclosporiasis	32 (73%)	2 (5%)	10 (23%)
Escherichia coli O157:H7	40 (77%)	5 (10%)	7 (13%)
Ehrlichiosis/Anaplasmosis	30 (68%)	5 (11%)	9 (20%)
Giardiasis	47 (98%)	0 (0%)	1 (2%)
Q Fever	36 (72%)	9 (18%)	5 (10%)
<i>S. pneumonia</i> , invasive, < 5 years of age	27 (59%)	0 (0%)	19 (41%)
S. pneumonia, invasive, all ages	35 (80%)	5 (11%)	4 (9%)
Varicella	32 (76%)	1 (2%)	9 (21%)
Vibriosis	36 (82%)	2 (5%)	6 (14%)
Average	34 (76%)	3 (7%)	8 (17%)

Reporting requirement	States
Any testing result in all ages	28 (57%)
Any testing result in a limited age	
group:	
• <6 years of age	4 (8%)
• <18 years of age	2 (4%)
Testing result at or above a	
threshold for all ages:	
• $\geq 2.3 \ \mu g/dl$	1 (2%)
• > 9 μ g/dl	1 (2%)
• $\geq 10 \ \mu g/dl$	3 (6%)
Testing result at or above a	
threshold in a limited age group:	
• <6 years of age, $\geq 10 \ \mu g/dl$	1 (2%)
• <13 years of age, \geq 5 µg/dl	1 (2%)
• <18 years of age, $\geq 10 \ \mu g/dl$	1 (2%)
• <18 years of age, $\geq 25 \ \mu g/dl$	1 (2%)
Different thresholds for a younger	
and older age group:	
• <6 years, \geq 5 µg/dl;	1 (2%)
\geq 6 years, \geq 10 µg/dl	
• <16 years, \geq all results;	1 (2%)
\geq 16 years, \geq 25 µg/dl	• • • • • •
• <16 years, \geq 10 µg/dl;	2 (4%)
\geq 16 years, \geq 25 µg/dl	1 (201)
• <18 years, \geq 5 µg/dl;	1 (2%)
\geq 18 years, \geq 10 µg/dl	1 (20/)
• <18 years, all results;	1 (2%)
\geq 18 years, \geq 25 µg/dl	

 Table 12. Difference in state blood lead reporting requirements (N=49)

Table 13. Differences in state pediatric influenza mortality reporting requirements (N=48)

Reporting requirement	States
Influenza mortality, pediatric (only)	27 (56%)
Influenza mortality, all ages	11 (23%)
Influenza mortality, under age 65	1 (2%)
Influenza mortality, infant	1 (2%)
Influenza	8 (17%)

Reporting requirement	States
Only explicitly listed in recommendation	4 (8%)
Only not explicitly listed in recommendation	11 (23%)
Both explicitly and not explicitly listed in recommendation	32 (67%)
No additional reporter types	1 (2%)

Table 14. Pediatric influenza mortality additional reporter types (N=48)

Table 15. STEC additional reporter types (N=52)

Reporting requirement	States
Only explicitly listed in recommendation	5 (10%)
Only not explicitly listed in recommendation	11 (21%)
Both explicitly and not explicitly listed in recommendation	35 (67%)
No additional reporter types	1 (2%)

Table 16. State tuberculosis reporting requirements (N=52)

Reporting requirement	States
Active TB only, no pharmacy reporting requirement	32 (62%)
Active TB only, includes pharmacy reporting requirement	12 (23%)
Active and latent TB, no pharmacy reporting requirement	7(13%)
Active and latent TB, includes pharmacy reporting requirement	1(2%)

Table 17. Tuberculosis additional reporter types (N=52)

Reporting requirement	States
Only explicitly listed in recommendation	5 (10%)
Only not explicitly listed in recommendation	11 (21%)
Both explicitly and not explicitly listed in recommendation	35 (67%)
No additional reporter categories	1 (2%)



Appendix C: Nationally Notifiable Condition State Reporting Requirements

Figure 17. State reporting requirements and timeframes for anaplasmosis (N=52)



Figure 18. State reporting requirements and timeframes for anthrax (N=52)



Figure 19. State reporting requirements and timeframes for arboviral diseases (N=52)



Figure 20. State reporting requirements and timeframes for babesiosis (N=52)



Figure 21. State reporting requirements and timeframes for botulism (N=52)



Figure 22. State reporting requirements and timeframes for brucellosis (N=52)



Figure 23. State reporting requirements and timeframes for campylobacteriosis (N=52)



Figure 24. State reporting requirements and timeframes for cancer (N=52)



Figure 25. State reporting requirements and timeframes for carbon monoxide poisoning (N=52)



Figure 26. State reporting requirements and timeframes for chancroid (N=52)



Figure 27. State reporting requirements and timeframes for *Chlamydia trachomatis* infection (N=52)



Figure 28. State reporting requirements and timeframes for cholera (N=52)



Figure 29. State reporting requirements and timeframes for coccidioidomycosis (N=52)



Figure 30. State reporting requirements and timeframes for congenital syphilis (N=52)



Figure 31. State reporting requirements and timeframes for cryptosporidiosis (N=52)



Figure 32. State reporting requirements and timeframes for cyclosporiasis (N=52)



Figure 33. State reporting requirements and timeframes for dengue virus infection (N=52)



Figure 34. State reporting requirements and timeframes for diphtheria (N=52)



Figure 35. State reporting requirements and timeframes for ehrlichiosis (N=52)



Figure 36. State reporting requirements and timeframes for elevated blood lead levels (N=52)


Figure 37. State reporting requirements and timeframes for foodborne disease outbreaks (N=52)



Figure 38. State reporting requirements and timeframes for giardiasis (N=52)



Figure 39. State reporting requirements and timeframes for gonorrhea (N=52)



Figure 40. State reporting requirements and timeframes for *Haemophilus influenza*, invasive disease (N=52)



Figure 41. State reporting requirements and timeframes for Hansen's disease (N=52)



Figure 42. State reporting requirements and timeframes for hantavirus infection (N=52)



Figure 43. State reporting requirements and timeframes for hantavirus pulmonary syndrome (N=52)



Figure 44. State reporting requirements and timeframes for hepatitis A, acute (N=52)



Figure 45. State reporting requirements and timeframes for hepatitis B, acute (N=52)



Figure 46. State reporting requirements and timeframes for hepatitis B, chronic (N=52)



Figure 47. State reporting requirements and timeframes for hepatitis B, perinatal (N=52)



Figure 48. State reporting requirements and timeframes for hepatitis C, acute (N=52)



Figure 49. State reporting requirements and timeframes for hepatitis C, past or present (N=52)



Figure 50. State reporting requirements and timeframes for HIV infection (N=52)



Figure 51. State reporting requirements and timeframes for hemolytic uremic syndrome, post-diarrheal (N=52)



Figure 52. State reporting requirements and timeframes for influenza pediatric mortality (N=52)



Figure 53. State reporting requirements and timeframes for invasive pneumococcal disease (N=52)



Figure 54. State reporting requirements and timeframes for legionellosis (N=52)



Figure 55. State reporting requirements and timeframes for leptospirosis (N=52)



Figure 56. State reporting requirements and timeframes for listeriosis (N=52)



Figure 57. State reporting requirements and timeframes for lyme disease (N=52)



Figure 58. State reporting requirements and timeframes for malaria (N=52)



Figure 59. State reporting requirements and timeframes for measles (N=52)



Figure 60. State reporting requirements and timeframes for meningococcal disease (N=52)



Figure 61. State reporting requirements and timeframes for mumps (N=52)



Figure 62. State reporting requirements and timeframes for novel influenza A virus infections (N=52)



Figure 63. State reporting requirements and timeframes for pertussis (N=52)



Figure 64. State reporting requirements and timeframes for pesticide injury and illness, acute (N=52)



Figure 65. State reporting requirements and timeframes for plague (N=52)



Figure 66. State reporting requirements and timeframes for polio, paralytic (N=52)



Figure 67. State reporting requirements and timeframes for poliovirus, non-paralytic (N=52)



Figure 68. State reporting requirements and timeframes for psittacosis (ornithosis) (N=52)



Figure 69. State reporting requirements and timeframes for Q fever (N=52)



Figure 70. State reporting requirements and timeframes for rabies, animal (N=52)



Figure 71. State reporting requirements and timeframes for rabies, human (N=52)



Figure 72. State reporting requirements and timeframes for rubella, congenital syndrome (N=52)


Figure 73. State reporting requirements and timeframes for rubella (N=52)



Figure 74. State reporting requirements and timeframes for salmonellosis (N=52)



Figure 75. State reporting requirements and timeframes for severe acute respiratory syndrome (SARS) (N=52)



Figure 76. State reporting requirements and timeframes for shigellosis (N=52)



Figure 77. State reporting requirements and timeframes for silicosis (N=52)



Figure 78. State reporting requirements and timeframes for smallpox (N=52)



Figure 79. State reporting requirements and timeframes for spotted fever rickettsiosis (N=52)



Figure 80. State reporting requirements and timeframes for staphyloccal toxic shock syndrome (N=52)



Figure 81. State reporting requirements and timeframes for Shiga-toxin producing *Escherichia coli* (N=52)



Figure 82. State reporting requirements and timeframes for streptococcal toxic shock syndrome (N=52)



Figure 83. State reporting requirements and timeframes for syphilis (N=52)



Figure 84. State reporting requirements and timeframes for tetanus (N=52)



Figure 85. State reporting requirements and timeframes for trichinellosis (N=52)



Figure 86. State reporting requirements and timeframes for tuberculosis (N=52)



Figure 87. State reporting requirements and timeframes for tularemia (N=52)



Figure 88. State reporting requirements and timeframes for typhoid fever (N=52)



Figure 89. State reporting requirements and timeframes for varicella deaths (N=52)



Figure 90. State reporting requirements and timeframes for varicella (N=52)



Figure 91. State reporting requirements and timeframes for vibriosis (N=52)



Figure 92. State reporting requirements and timeframes for viral hemorrhagic fever (N=52)



Figure 93. State reporting requirements and timeframes for vancomycin-intermediate *Staphylococcus aureus* (VISA) (N=52)



Figure 94. State reporting requirements and timeframes for vancomycin-resistant *Staphylococcus aureus* (VRSA) (N=52)



Figure 95. State reporting requirements and timeframes for waterborne disease outbreaks (N=52)



Figure 96. State reporting requirements and timeframes for yellow fever (N=52)

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Curriculum Vitae

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EDUCATION

- University of Nevada, Las Vegas Doctor of Philosophy, Public Health, PhD Candidate, expected graduation December, 2015
- University of California, Berkeley Master of Science, Infectious Diseases: May 2000
- Purdue University Bachelor of Science, Biology: May 1997

PROFESSIONAL EXPERIENCE

Adjunct FacultySchool of Community Health Sciences, University of Nevada, Las Vegas1/06-Present

- Taught graduate courses in infectious disease epidemiology, disease surveillance and outbreak investigation
- Served on MPH student committees

Senior Epidemiologist

Southern Nevada Health District, Las Vegas, NV

8/02-Present

- Created, implemented, maintained and evaluated disease surveillance systems, including the development of a novel patient complaint-based syndromic surveillance system for communicable diseases and a sentinel physician respiratory disease surveillance system.
- Lead investigations of numerous outbreaks of foodborne disease, respiratory disease, vaccine preventable disease and healthcare-acquired disease in Las Vegas.
- Lead the investigation of the largest outbreak of healthcare-acquired hepatitis C in United States history, with 63,000 exposed patients. Conducted field investigation; developed, implemented and analyzed questionnaires; responded to media requests for information and interviews; testified to the state legislature and briefed Nevada's congressional delegation; assisted in the development of new statutes and regulations; testified in the criminal trial resulting in the conviction of the responsible physician for murder and several civil trials resulting in over \$1 billion in judgments against various defendants.

- Wrote county disease reporting regulations and lead the process of public hearings and approval by the local and state boards of health. Participated in multiple revisions of state health regulations, including drafting language and testifying on behalf of the agency at state board of health meetings.
- Represented the agency and the state in numerous national meetings and conferences, as part of various workgroups, and during public health exercises.
- Developed public health informatics projects including a foodborne illness complaint system, the health alert network system, systems for tracking information during outbreaks, and electronic laboratory report processing. Participated in requirements gathering, gap analysis, and the selection of an open-source disease surveillance system and the development of in-house electronic laboratory reporting processing, and served as the subject matter expert during implementation, ongoing maintenance and enhancement.
- Conducted studies
- Served as the office media spokesperson, giving several hundred live and recorded interviews on various topics for print, television and radio for local, national and international media.

Epidemiologist

Southern Nevada Health District, Las Vegas, NV 6/01-8/02

- Interviewed people with communicable diseases, arranged prophylaxis and conducted work exclusions
- Participated in outbreak investigations
- Assisted in the development of bioterrorism preparedness training for clinicians

PUBLICATIONS

Kriseman J and **Labus B**. Local and regional public health informatics, chapter in Public health informatics and information systems, J.A. Magnuson, P.C. Fu, Jr. (eds.), Springer-Verlag London. 2014.

St. Jacques K, Cruz P, **Labus B**. Analysis of the morbidity and mortality of severe influenza infection in Clark County, Nevada for the 2010-2011 influenza season. Nevada Journal of Public Health. 2013.

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