NAVAL POSTGRADUATE SCHOOL

MONTEREY, CALIFORNIA

THESIS

BIOSURVEILLANCE TECHNOLOGY: PROVIDING SITUATIONAL AWARENESS THROUGH INCREASED INFORMATION SHARING

by

Jasie K. Logsdon

September 2011

Thesis Co-Advisors: Richard Bergin
Robert Josefek

Approved for public release; distribution is unlimited

THIS PAGE INTENTIONALLY LEFT BLANK

REPORT DOCUMENTATION PAGE			Form Approved OMB No. 0704-0188
Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instruction, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to Washington headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188) Washington DC 20503.			
1. AGENCY USE ONLY ***(Leave blank)***	**2. REPORT DATE** September 2011	**3. REPORT TYPE AND DATES COVERED** Master's Thesis	
4. TITLE AND SUBTITLE Biosurveillance Technology: Providing Situational Awareness through Increased Information Sharing		**5. FUNDING NUMBERS**	
6. AUTHOR(S) Jasie K. Logsdon			
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Naval Postgraduate School Monterey, CA 93943-5000		**8. PERFORMING ORGANIZATION REPORT NUMBER**	
9. SPONSORING /MONITORING AGENCY NAME(S) AND ADDRESS(ES) N/A		**10. SPONSORING/MONITORING AGENCY REPORT NUMBER**	
11. SUPPLEMENTARY NOTES The views expressed in this thesis are those of the author and do not reflect the official policy or position of the Department of Defense or the U.S. government. IRB Protocol number NPS.2011.0042-IR-EP7-A_.			
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for public release; distribution is unlimited		**12b. DISTRIBUTION CODE** A	

13. ABSTRACT (maximum 200 words)

This need for the public health and medical enterprise to share information, has increased over the last decade, due to events such as the Severe Acute Respiratory Syndrome (SARS) outbreak, natural disasters, such as Hurricane Katrina, the 2009 H1N1 influenza outbreak, and other naturally occurring outbreaks, such as the recent Shiga toxin-producing E. coli O104 (STEC O104:H4) infections occurring in, and associated with, travel to Germany.

This thesis explores the various ways that information sharing can be improved within the public health and medical enterprise. Through case studies and interviews, a conceptual framework, the LEAPS model, was developed to guide the process to improve information sharing. This model is based upon the establishment of a strong foundation in health information sharing and disease surveillance. This model is centered upon leadership, policy, and strategy. The LEAPS model framework is then expanded to offer specific ways for the public health and medical enterprise to improve information sharing within jurisdictions and sectors to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture.

14. SUBJECT TERMS public health, information sharing, biosurveillance, situational awareness, common operating picture, medical, disease surveillance, syndromic surveillance, disease reporting, bioterrorism, LEAPS model			**15. NUMBER OF PAGES** 141
			16. PRICE CODE
17. SECURITY CLASSIFICATION OF REPORT Unclassified	**18. SECURITY CLASSIFICATION OF THIS PAGE** Unclassified	**19. SECURITY CLASSIFICATION OF ABSTRACT** Unclassified	**20. LIMITATION OF ABSTRACT** UU

NSN 7540-01-280-5500 Standard Form 298 (Rev. 2-89)
Prescribed by ANSI Std. 239-18

THIS PAGE INTENTIONALLY LEFT BLANK

Approved for public release; distribution is unlimited

BIOSURVEILLANCE TECHNOLOGY: PROVIDING SITUATIONAL AWARENESS THROUGH INCREASED INFORMATION SHARING

Jasie K. Logsdon
Senior Epidemiologist, Lake Cumberland District Health Department, KY
BS, Cumberland College, 2001;
MPH, University of Kentucky, 2003

Submitted in partial fulfillment of the
requirements for the degree of

MASTER OF ARTS IN SECURITY STUDIES
(HOMELAND SECURITY AND DEFENSE)

from the

NAVAL POSTGRADUATE SCHOOL
September 2011

Author: Jasie K. Logsdon

Approved by: Richard Bergin
Thesis Co-Advisor

Robert Josefek
Thesis Co-Advisor

Harold A. Trinkunas, PhD
Chair, Department of National Security

THIS PAGE INTENTIONALLY LEFT BLANK

ABSTRACT

This need for the public health and medical enterprise to share information has increased over the last decade, due to events such as the Severe Acute Respiratory Syndrome (SARS) outbreak, natural disasters, such as Hurricane Katrina, the 2009 H1N1 influenza outbreak, and other naturally occurring outbreaks, such as the recent Shiga toxin-producing E. coli O104 (STEC O104:H4) infections occurring in, and associated with, travel to Germany.

This thesis explores the various ways that information sharing can be improved within the public health and medical enterprise. Through case studies and interviews, a conceptual framework, the LEAPS model, was developed to guide the process to improve information sharing. This model is based upon the establishment of a strong foundation in health information sharing and disease surveillance. This model is centered upon leadership, policy, and strategy. The LEAPS model framework is then expanded to offer specific ways for the public health and medical enterprise to improve information sharing within jurisdictions and sectors to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture.

THIS PAGE INTENTIONALLY LEFT BLANK

TABLE OF CONTENTS

THIS PAGE INTENTIONALLY LEFT BLANK

LIST OF FIGURES

THIS PAGE INTENTIONALLY LEFT BLANK

LIST OF TABLES

THIS PAGE INTENTIONALLY LEFT BLANK

LIST OF ACRONYMS AND ABBREVIATIONS

BAR	BioWatch Actionable Results
BDS	Biohazard Detection System
CAP	Common Alerting Protocol
CDC	Centers for Disease Control and Prevention
CDC HAN	Centers for Disease Control and Prevention Health Alert Network
CDESS	Communicable Disease Electronic Surveillance System
Com Dir	Communications Directory
DHS	Department of Homeland Security
DoD	Department of Defense
EARS	Early Aberration Reporting System
ECLRS	Electronic Clinical Laboratory Reporting System
EDB	Executive Dashboard
ESSENCE	Electronic Surveillance System for the Early Notification of Community-based Epidemics
FOIA	Freedom of Information Act
GAO	United States Government Accountability Office
HCS	Health Commerce System
HERDS	Hospital Emergency Response Data System
HIPAA	Health Insurance Portability and Accountability Act of 1996
HSPD	Homeland Security Presidential Directive
IHANS	Integrated Health Alerting and Notification System
IHR 2005	International Health Regulations
ILI	Influenza-like Illness
IOM	Institute of Medicine
IT	Information Technology
LHD	Local Health Department
MOH	Medical Officers of Health
NBIC	National Biosurveillance Integration Center
NBIS	National Biosurveillance Integration System
NCMI	National Center for Medical Intelligence

NHSS	National Health Security Strategy
NRC	National Research Council
NRF	National Response Framework
NRDM	National Retail Data Monitor
NYSDOH	New York State Department of Health
PAHPA	Pandemic and All Hazards Preparedness Act of 2006
PCA	PHIN Communication and Alerting Guide
PHEP	Public Health Emergency Preparedness
PHIN	Public Health Information Network
PHI	Public Health Investigators
RODS	Real-Time Outbreak and Disease Surveillance
RTBP	Real-Time Biosurveillance Program
SMS	Short Message Service
TCWI	T-Cube Web Interface
US	United States
WHO	World Health Organization
WRCD	Weekly Return of Communicable Disease

ACKNOWLEDGMENTS

The completion of this master's program and this thesis has required a significant amount of support from so many people. I could not have accomplished this without this incredible network of support.

First and foremost, without the support of my parents, I would not be where I am today. They have always been my biggest supporters. I cannot begin to express my gratitude for all they have done to help me through this program and throughout my life.

Thanks to my friends and co-workers for all of their support and for picking up the slack while I was gone. The notes, e-mails, and phone calls of support as well as knowing that you were celebrating with me after each milestone have meant so much to me over the past 18 months. To Jessica Gover and Jane Jones for keeping the LCDHD Preparedness Program running, I always had complete and total faith that you had everything under control and you would excel at every task. To the nurses and environmentalists at LCDHD that made sure disease surveillance, investigations, and reporting were taken care of while I was gone, I will forever be in your debt.

Thanks to those who endorsed my attendance. My organization, specifically the Medical Director, Dr. Christine Weyman, and the Executive Director, Shawn Crabtree, for allowing me to seize this opportunity. Thomas W. Samuel, JD, MBA, and Doug Thoroughman, PhD, MS, for their letters of recommendation, support, and encouragement throughout this program.

A special thanks to Cohorts 1001/1002 for making this an unbelievable experience for me. You are a great group of people whom I am now privileged to call friends. The support network within this cohort has been instrumental in my success. I have learned so much from each one of you. The e-mails, phone calls, and texts kept me going. I am going to miss our times in Monterey and hope that we can keep in touch. It has truly been a pleasure!

I would like to thank the NPS CHDS community. This has been an experience that I will not soon forget. The instructors and guest lecturers were top-notch. I have

learned so much more than I ever thought possible. The network of professionals that is being built through this program is second-to-none.

Last, but not least, to my co-advisers, Richard Bergin and Robert Josefek, I am not sure that thank you is enough. I truly appreciate your assistance and perseverance through this thesis process. Your guidance and support was invaluable.

I must say it has been a true blessing and privilege to have had the opportunity to be a part of this program. I thank God for leading me to this opportunity and for giving me the courage to seize it.

I. INTRODUCTION

A. PROBLEM STATEMENT

The rapid emergence of new diseases and the resurgence of old diseases coupled with the threats of biological, chemical, and radiological terrorism underscore the need for a worldwide effort to improve situational awareness, common operating picture, and outbreak detection capabilities. The rapid detection and response to disease outbreaks is paramount to mitigating the effects of disease on the population of the United States. This is vitally important for high consequence outbreaks such as pandemic influenza or an attack with a biological, chemical, or radiological agent. At present, the United States does not have a robust and integrated information-sharing system, which is crucial to the early detection of an outbreak or exposure. Such a system provides situational awareness and a common operating picture during an event and aids in the execution of an appropriate countermeasures response.

The *Homeland Security Act* of 2002, the *Public Health Security and Bioterrorism Preparedness and Response Act* of 2002, the *Pandemic and All Hazards Preparedness Act* of 2006 (PAHPA), *Homeland Security Presidential Directives* (HSPD) 9, 10, and 21, and, most recently, the *National Health Security Strategy* (NHSS) have called for the protection of the health of Americans by facilitating information sharing across all sectors and jurisdictions in regards to health-related threats and events. In response to this legislation and the HSPDs, the federal government has invested millions of dollars in the development and implementation of numerous separate and independent disease surveillance and biosurveillance systems. Despite the millions of dollars invested, there was very little planning before these disparate systems were created and little, if any, coordination between systems. Many of these systems are duplicative and most are not interoperable, causing vital information to be stovepiped and inaccessible.

Recognizing the investments and infrastructure currently in place for disease surveillance and biosurveillance, the challenge lies in the integration of those systems to engender efficient information sharing across all health sectors. Existing surveillance

systems provide minimal and largely ineffective situational awareness and a common operating picture, thereby hindering rapid and effective response to public health events of local, regional, national, or international significance.

To put this issue in the proper context, the 2009 H1N1 influenza outbreak can be examined. This particular influenza virus demonstrated the ease by which influenza can be transmitted by a global society; however, it was relatively mild in comparison to the initial planning scenarios and projections. Had this virus been more virulent, like the 1918 Spanish influenza the effects on the world's population could have been much worse. The fact that the national and global surveillance systems were not integrated and information was not shared in a timely manner could have had disastrous effects on the world's population.

Millions of dollars have been invested, legislation has been passed, and there have been multiple HSPDs in an effort to enable the United States to more rapidly detect disease outbreaks. However, the existing systems do not facilitate information-sharing across the health and medical or homeland security enterprise, making it difficult for agencies to quickly mount appropriate countermeasures responses and to maintain situational awareness and a common operating picture. The rapidly evolving and ever increasing number of health threats in the world only serves to further emphasize the need for better information sharing across all jurisdictions and levels.

B. RESEARCH QUESTIONS

1. Primary Question

- How can the public health/medical enterprise improve information-sharing across jurisdictions and sectors to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture?

2. Secondary Questions

- What systems are currently used to provide situational awareness and a common operating picture during naturally occurring or intentional disease outbreaks or exposures, and what are the current limitations of these systems?

- What are the barriers to information sharing in the current public health/medical enterprise?
- How can the current systems be used, and what further actions can be taken to more rapidly detect and respond to outbreaks and to create better situational awareness and a common operating picture?

C. LITERATURE REVIEW

Biosurveillance and public health disease surveillance literature is abundant. Literature regarding public health disease surveillance has a long history. However, literature regarding biosurveillance, public health information sharing, and situational awareness is relatively new, with most literature being written after the events of September 11, 2001. This is primarily due to the increased emphasis upon the United States' ability to rapidly detect and respond to intentional and unintentional disease outbreaks. Numerous sources of literature have been identified to guide the analysis and understanding of this topic; however, the scope of the literature reviewed will be confined to that written after 2000, as this is when biosurveillance was recognized as an important component of overall health and homeland security.

The literature is diverse and includes documents from academia, advocacy groups, the federal government, professional journals, and government-funded projects. For the purposes of this literature review, the documents will be divided by the following methodology:

1. Literature on the integration and coordination of current surveillance and biosurveillance systems
2. Literature discussing the overarching barriers to information-sharing and those specific to health information sharing
3. Literature pertaining to existing surveillance and biosurveillance systems and how they can be used to improve situational awareness

The abundance of literature on this topic, especially recent government reports, speaks to the relevance, and significance of this topic. It reflects the awareness at the state, local, and national level of the importance of the efforts to develop a more robust system for the detection and response to naturally occurring or intentional disease outbreaks.

1. Integration and Coordination of Current Systems

There is a significant amount of literature that discusses the need for integration and coordination of current disease surveillance systems; however, most do not offer a strategy to achieve this. The literature discusses the importance of an integrated biosurveillance system, and how that will facilitate the rapid detection and response to health threats. HSPD 21 provides the overall directive, necessary components and identifies stakeholders. It discusses the need for a "nationwide, robust, and integrated biosurveillance capability," which includes the integration of data from various sources (international, human and animal health, agricultural, environmental), to provide a nationwide common operating picture (White House, 2008).

The intent of the 2010 *National Biosurveillance Strategy for Human Health* is to serve as a guide for implementation of a national network of biosurveillance (Centers for Disease Control and Prevention Office of Public Health Preparedness and Response Biosurveillance Coordination Unit [CDC Biosurveillance Coordination Unit], 2010). It discusses the need for a "system of systems" that fully uses the local level data collection and analysis (CDC Biosurveillance Coordination Unit, 2010). It goes on to discuss that biosurveillance efforts occurring at the state and local level allow for the interpretation and application of data in a local context, which can be supplemented and improved by national level data to provide a common operating picture (CDC Biosurveillance Coordination Unit, 2010). However, this report does not offer a strategy for creating such a system.

Specifically, the literature discusses national efforts such as the Public Health Information Network (PHIN), the National Biosurveillance Integration Center (NBIC), the National Biosurveillance Integration System (NBIS), and the National Center for Medical Intelligence (NCMI). The Center for American Progress report *Biosecurity: A Comprehensive Action Plan* discusses both the PHIN and the NBIS. The PHIN is a CDC effort to integrate state, local, and federal surveillance systems to create a unified network (Grotto & Tucker, 2006). The report describes the NBIS as the government's foremost initiative to develop "an integrated and comprehensive bio-surveillance system" linking surveillance efforts across jurisdictions and entities (Grotto & Tucker, 2006). The GAO

report *Biosurveillance: Developing a Collaboration Strategy is Essential to Fostering Interagency Data and Resource Sharing* discusses the Department of Homeland Security (DHS) efforts to use the NBIS to develop the NBIC, an IT system that will integrate, analyze, and disseminate various biosurveillance and disease surveillance system's data (Jenkins, W. O., Laffoon, A., Cooper, M., Dowdle, C., Godfrey, K., & Yohe, A., 2009).

There is not a significant amount of literature to be found pertaining to the NCMI. A 2009 Department of Defense instruction document outlines the purpose and mission of the NCMI, stating, "NCMI is the DoD lead activity for the production of medical intelligence," including "integrated, all-source intelligence" on health threats for the DoD and other government and international entities (United States Department of Defense [DoD], 2009). However, in reading *Enclosure 2* of the DoD instruction document, it seems the primary focus of the NCMI is to provide medical intelligence for the benefit and use of the military, with some ancillary intelligence being provided to the Intelligence Community.

As noted above, the literature contains a vast amount of information pertaining to the need to integrate and coordinate existing surveillance systems nationwide. The literature adequately demonstrates the importance of an integrated system in respect to providing near real-time situational awareness. Nonetheless, it offers no roadmap or plan for state, local, and national surveillance and/or biosurveillance systems integration.

2. Information-Sharing Barriers

Barriers to information-sharing are many and are cited throughout the literature. The barriers are similar throughout the various disciplines that collect and share information and intelligence. The literature cites legal barriers, cultural barriers, and process oriented barriers as challenges to information sharing.

a. Legal Barriers

The National Security Telecommunications Advisory Committee discusses legal barriers in reference to critical infrastructure, in its report *Legislative and Regulatory Task Force Report: Barriers to Information-sharing* (2003). This report cites

barriers to information sharing, which include the concern that critical infrastructure information might be disclosed under Freedom of Information Act (FOIA) requests; the industry might face civil tort or contract liability issues; or there could be antitrust violations (National Security Telecommunications Advisory Committee, 2003). Many of these issues carry over into the health information-sharing arena as well.

Legal Impediments to Surveillance for Biological Threats and Countering Terrorism offers insight into the legal barriers that exist within public health and medical information-sharing (Sutton, 2002). Public health law is a constitutionally reserved power of the states, as awarded by the Tenth Amendment. Furthermore, the report states, there is no law that exists that requires states to share their infectious disease information with federal officials and agencies (Sutton, 2002). Because public health law is a state power, each states' laws are different and do not always facilitate information sharing between states or between the states and the federal government. This report goes on to discuss information privacy issues associated with surveillance as a barrier to information-sharing (Sutton, 2002).

b. Cultural Barriers

The United States Department of Justice *Law Enforcement Information-sharing Program* discusses the need to move from a "need to know" culture to a "need to share" culture (United States Department of Justice [DOJ], 2005). Specifically relating to health information-sharing, the GAO Report *Biosurveillance: Developing a Collaboration Strategy is Essential to Fostering Interagency Data and Resource Sharing*, cites issues with "confusion, uncertainty, and skepticism" about the value of participation and "the mission and purpose" of the National Biosurveillance Integration Center has led to a lack of willingness to share information (Jenkins et al., 2009). This report goes further to discuss cultural barriers such as trust and control over sensitive information, specifically prior to being vetted and verified.

c. Process-Oriented Barriers

The 2009 *Information-sharing Report to Congress* discusses the inconsistencies in processes and procedures for handling and safeguarding information

and that state, local, and tribal policies may differ greatly from the federal policies (Program Manager, Information Sharing Environment, 2009). The GAO Report *Biosurveillance: Developing a Collaboration Strategy is Essential to Fostering Interagency Data and Resource Sharing* discusses the scant availability of data throughout the federal government primarily because most of the data and information needed for biosurveillance activities is generated and owned outside of the federal government (Jenkins et al., 2009). According to the literature, state and local governments and private entities are predominantly the agencies that own the data needed for biosurveillance activities, and many of these entities are reluctant to conform to the standards set forth by the federal government for data sharing.

The barriers to information sharing are numerous and are sometimes deeply ingrained within the discipline. The literature cites barriers within various domains—legal, cultural, and process oriented. There have been numerous reports published regarding information sharing and the barriers that exist, not only within the health and medical field, but within and among numerous entities. It is interesting to note that even though the literature pertains to different disciplines, often times the barriers are the same.

Although there is abundant literature published on the topic, there has been very little progress made to address the information-sharing barriers that exist within the public health/medical enterprise. The literature offers very little guidance and virtually no recommendations to address this issue. The literature does an excellent job of outlining the challenges to information sharing; however, it does not offer a strategy to address those barriers to create an information-sharing environment that enables near real-time situational awareness and common operating picture. Until a strategy is developed, there can be only limited progress toward an integrated biosurveillance system in the United States.

3. Existing Systems, How They Can be Used, and Their Limitations

The literature that exists in regard to existing disease surveillance and biosurveillance systems and how they can be used is extensive. Some of the literature encourages the use of current disease surveillance and biosurveillance systems to accomplish the goals of biosurveillance.

The GAO Report *Biosurveillance: Efforts to Develop a National Biosurveillance Capability Need a National Strategy and a Designated Leader* outlines the capability needs for biosurveillance—systems and equipment that rapidly detect and communicate the indicators of an event, quick analysis, and timely dissemination to decision makers (Jenkins et al., 2010). The literature discusses the local, state, and national disease surveillance and biosurveillance systems at great length, including the fact that these are the foundation for a national biosurveillance system.

In his 2003 testimony on *CDC's Disease Surveillance System Efforts* before the subcommittee on Emergency Preparedness and Response, Select Committee on Homeland Security, United States House of Representatives, Joseph M. Henderson, M.P.A., Director of the Office of Terrorism Preparedness and Emergency Response at the CDC, discusses how disease detection almost always occurs at the local level, usually by an astute clinician who reports the occurrence to the local health department (Henderson, 2003).

Most of the systems and capabilities the literature discusses are national systems that can be used by state and local entities to enhance and augment state and local systems. These include initiatives that track non-traditional data such as school absenteeism, over-the-counter medication sales, and syndromic surveillance. Syndromic surveillance is covered extensively in the literature; however, there is no clearly articulated consensus on the value of the information collected by syndromic surveillance systems. The most extensive and comprehensive review of federal level biosurveillance and disease surveillance systems is contained in the 2010 GAO Report *Biosurveillance: Efforts to Develop a National Biosurveillance Capability Need a National Strategy and a Designated Leader* (Jenkins et al., 2010). Appendix IV of this report provides an

overview of federal systems, including the agency/department responsible for oversight of the system, the information collected, primary users and primary providers of data, the system status, diseases of concern, and the type of information available from the system (Jenkins et al., 2010).

The Stimson Center report, *New Information and Intelligence Needs in the 21st Century Threat Environment,* contains a relatively comprehensive list of national and international disease surveillance systems (Fischer et al., 2008). Additionally, a whitepaper from the University of Pittsburgh Medical Center, Center for Biosecurity titled *Creating Situational Awareness: A Systems Approach,* offers a listing of existing systems and programs beyond federal disease surveillance and biosurveillance systems that relate to healthcare situational awareness and contribute or could contribute to biosurveillance activities (Toner, 2009).

a. Limitations of Current Systems

From a review of the literature, it is evident that there is a vast amount of information and data collected through various mechanisms of biosurveillance and disease surveillance systems. The whitepaper *Creating Situational Awareness: A Systems Approach*, states that although these surveillance efforts absolutely provide information flows that did not exist before, it is not clear to what extent they have enabled a more robust understanding of disease outbreaks (Toner, 2009). This whitepaper goes further to state that the systems that exist are used primarily to detect outbreaks, not to manage them and they do not have a clear concept of operations (Toner, 2009). There has been a lot of technology pushed into the field but there is not a lot of science behind the technology (Toner, 2009).

As mentioned earlier, the literature discusses syndromic surveillance and debates its merits for use to provide situational awareness. *Creating Situational Awareness: A Systems Approach* discusses the issues with syndromic surveillance, including the fact that these systems did not seem to provide an adequate picture of the scope of the outbreak quickly enough (Toner, 2009). This report discusses CDC's ILInet data on outpatient visits to sentinel physician offices, which is traditionally reported on a

weekly basis—not timely enough to identify emerging influenza outbreaks or provide decision makers with near real-time data for decisions regarding interventions (Toner, 2009). One very interesting finding regarding syndromic surveillance, according to Toner, is that a large outbreak of a clinically mild disease may not be detected by syndromic surveillance systems because these systems are designed to look for people who are sick enough to seek medical treatment and care (Toner, 2009).

The *National Health Security Strategy* discusses the need for public health to be able to leverage the resources and to be coordinated with the organizations responsible for oversight of food safety, environmental protection, and workplace safety (United States Department of Health and Human Services [HHS], 2009). This strategy specifically notes that improvements are needed in monitoring for emerging infectious agents, including zoonotic and agricultural disease threats; vector surveillance; and health impacts of climate change (HHS, 2009).

The *Draft Biennial Implementation Plan for the National Health Security Strategy for the United States of America* points out organizational and structural gaps that are barriers to the coordination of the existing systems and data (United States Department of Health and Human Services [HHS], 2010). It points out that currently there is no overarching organizational structure that ensures coordination of the disparate systems, and no entity has been given the authority to implement specific activities related to biosurveillance and disease surveillance (HHS, 2010).

One of the elements the literature does not address in regard to system limitations is whether these systems have the ability to share data and information between systems. The ability to share information between systems depends upon interoperability of systems and data standards. Neither data standards, nor system interoperability, are discussed in the literature. These are two important components that are necessary for successful integration of systems.

Overall, the literature provides a fairly comprehensive review of the vast amount of disease surveillance and biosurveillance systems that are currently in operation. It provides an adequate view of the systems' capabilities and limitations.

However, there are areas that the literature does not delve into, such as the process for creating an integrated national biosurveillance system, which addresses data standards and interoperability challenges, policies, and a suggested format or structure for an integrated system.

D. CONCLUSION

Overall, the literature provides a broad look at information-sharing barriers, existing surveillance and biosurveillance systems, and the need for an integrated national biosurveillance enterprise. It demonstrates the importance of biosurveillance in ensuring the health of our nation. However, it fails to address the underlying issues in regard to information sharing and only offers broad recommendations for improving the national biosurveillance enterprise.

The literature comes from a wide range of sources, including works from academia, advocacy groups, the federal government, professional journals, and government funded projects. It provides a fairly comprehensive examination of existing surveillance and biosurveillance systems, which includes a description of the strengths and weaknesses of each system, a historical perspective on the evolution of the biosurveillance systems, and a glimpse of possible future advancements. It is clear by the abundance of literature pertaining to the various disease surveillance and biosurveillance systems nationally and internationally that a comprehensive evaluation of all surveillance and biosurveillance systems is beyond the scope of this project. Therefore, this study will focus on improving information sharing across jurisdictions and sectors to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture.

The literature provides a general overview of the barriers to information-sharing. Although there is an abundance of literature pertaining to existing biosurveillance systems, the literature neglects to discuss the limitations to information-sharing between these systems, including data standards and interoperability issues, nor does it go into great detail concerning strategies to address those barriers. This lack of attention to strategy development is a fundamental roadblock in seeking to leverage disease

surveillance and biosurveillance systems. It makes no policy recommendations or provides no solutions to removing the information-sharing barriers so that the national biosurveillance effort can be more effective in enhancing situational awareness and providing a common operating picture during events of public health significance.

There is a consensus within the literature that existing state, local, and federal disease surveillance and biosurveillance systems must be integrated to achieve near-real time situational awareness; however, it offers very little guidance for achieving this. The literature provides an effective argument that integration is the mechanism by which intentional and un-intentional disease outbreaks will be more rapidly detected, enabling a decisive response and implementation of appropriate countermeasures. It provides general recommendations for the creation and implementation of a national integrated biosurveillance system; however, the literature does not identify a leader for the endeavor nor does it discuss specific plans for implementation of this endeavor. It makes broad policy statements but does not make specific recommendations.

It is evident in the review of existing documents that the public health and medical information-sharing and biosurveillance enterprise has evolved and will continue to evolve to meet the ever-changing challenges facing the United States. What is lacking in the literature is a clear detailed policy and roadmap for creation and implementation of a strategy to improve information sharing within the public health and medical enterprise or the creation of a nationwide biosurveillance system.

E. TENTATIVE SOLUTIONS

For the nation to be prepared to detect, respond to, and recover from a bioterrorist attack or a naturally occurring disease outbreak, information-sharing, situational awareness, and common operating picture should be improved. To achieve this, traditional disease surveillance capabilities and biosurveillance capabilities at the local, state, and national level ought to be integrated. The integration of these systems could provide local, state, and federal public health authorities and the larger homeland security enterprise with situational awareness and a common operating picture, which is essential to mitigation, response, and recovery from events of public health significance.

An integrated approach to biosurveillance could be developed by the federal government. This integrated national biosurveillance system can include data from state and local data collection systems and may provide state and local public health authorities the ability to generate local situational awareness and common operating picture in addition to providing access to national-level intelligence and information. The NBIC at DHS is the center in which all biosurveillance data from other federal agencies, local, state, and private sector agencies could be fused and disseminated. The keys to success are getting all levels of stakeholders to agree to share information with the NBIC and to develop the necessary infrastructure to collect information from these partners.

1. Why Should the Local, State, and Federal Systems Be Integrated?

The rapid detection and response to disease outbreaks or exposures is essential to mitigating the effects of disease on the population. A robust and integrated information-sharing system is crucial to the early detection of an outbreak or exposure; providing situational awareness and a common operating picture during an event; and the execution of an appropriate countermeasures response. This is vitally important for outbreaks such as pandemic influenza or an attack with a biological, chemical, or radiological agent, which have the potential to be a high consequence event.

There have been numerous disease outbreaks over the past few years that provide a strong argument for the need to integrate surveillance systems from the local to the federal level. None of the recent national disease outbreaks resulted from bioterrorism or intentional contamination of food or water supplies; however, they caused significant illness and greatly impacted the economy. A recent example is the 2010 *Salmonella* Enteritidis outbreak associated with shell eggs. Initial cases were identified in Minnesota in May 2010, and the preliminary identification of the source of the outbreak was identified two months later in July 2010, as cases continued to increase. Recalls of the implicated shell eggs from identified egg suppliers did not begin until mid-August 2010 (Centers for Disease Control and Prevention, 2010). At this point, this outbreak has caused over 1900 people to become ill, with the potential for many still unaccounted for

because of the amount of time from illness onset to the time the illness is reported—typically two to three weeks but can potentially take up to six weeks (Centers for Disease Control and Prevention, 2010).

This outbreak, along with many others, demonstrates the need for a robust and integrated biosurveillance system. This system would allow local data entry pertaining to an outbreak and provide local situational awareness and common operating picture. This locally entered data could be visible to state and federal partners and fused with data from other jurisdictions and agencies, generating near real-time situational awareness and common operating picture across jurisdictions, thus allowing for a more rapid detection and response.

2. What Data Is Needed?

Biosurveillance demands more than traditional public health disease surveillance data. Multiple types of data are needed for biosurveillance. HSPDs 9 and 10, along with the Implementing Recommendations of the 9/11 Commission Act of 2007, specify the data that must be collected for biosurveillance. This includes data on human, animal, and plant health, food, and water quality (Jenkins et al., 2010). There are numerous sub-categories of data within these primary categories that are valuable in the overall biosurveillance effort and serve to enhance situational awareness and common operating picture. Some examples are: pre-diagnostic health data, over-the-counter medication sales, laboratory data, air monitoring, and drinking water monitoring. Open-source data, such as Google Flu Trends, Pro-Med Mail, newspaper headline searches, and social media must be included in biosurveillance data collection. International health data is also important to biosurveillance efforts, as it assists in the prediction of possible disease threats to the U.S.

3. Who Should Supply the Data?

Biosurveillance data could be collected from the local and state level, as this is the predominant source of data collection. With assistance from grants from the federal government, local, and state public health agencies have invested billions of dollars in disease surveillance and biosurveillance efforts. States and localities have developed

disease surveillance and reporting systems, syndromic surveillance systems, outbreak management systems, and other biosurveillance systems and tailored them to meet their local needs and standards. These systems have been effectively operating independently, meeting the needs at the state and local level. According to Jenkins et al., in the GAO Report *Biosurveillance: Efforts to Develop a National Biosurveillance Capability Need a National Strategy and a Designated Leader*:

> The responsibility and capacity for collecting most information related to plant, animal and human health, food, and environmental monitoring resides within state, local, and tribal governments, or private sector entities—such as hospital and other private health care providers. (Jenkins et al., 2010)

Since most of the data exists within the local and state government or private sector, it is absolutely essential that the federal government partner with these agencies.

The federal agencies that independently collect biosurveillance data or that receive, analyze, and fuse state and local data could allow for their data collection systems to be integrated in to the national biosurveillance system. Examples of this are the Environmental Protection Agency, United States Department of Agriculture, the Food and Drug Association, and Department of Interior.

4. How Should the Systems Be Integrated?

The integration of existing state and local disease surveillance and biosurveillance systems with federal systems is not an easy task. It will require a larger investment by the federal government in order to achieve this mission. The integration could take a "systems of systems" approach. State and local stakeholders have existing systems and processes for disease surveillance, reporting, and biosurveillance, which will not be easily changed or adapted. There are also private sector data sources that can be integrated, which use proprietary systems and share limited information with the public sector. For this reason, national level systems need to have the ability to connect to and receive data from local and state systems, which can then be analyzed, fused, and disseminated to stakeholders vertically and horizontally, across the health and homeland security spectrum.

Additionally, national-level biosurveillance initiatives may be coordinated and the data produced by them shared with the National Biosurveillance Integration Center (NBIC). This includes the efforts by the Centers for Disease Control BioPHusion Center, the Department of Defense National Center for Medical Intelligence, and other federal level initiatives. These actions might ensure achievement of a "national, robust, and integrated biosurveillance capability that provides timely warning and ongoing characterization of catastrophic biological events, drawing on the systems, resources, and information from existing human, animal, plant, food, and environmental surveillance activities" (Jenkins et al., 2010).

For the United States to be prepared to confront the next event of public health significance (pandemic, biological attack, or naturally occurring disease outbreak), an integrated approach could be developed and led by the federal government. For overall situational awareness and common operating picture, data must be collected, analyzed and fused from local, state, federal, international, and private sector agencies. The NBIC, through its "integration of biosurveillance elements and other data (including human health, animal health, agricultural, meteorological, environmental, intelligence, and other data)" has the ability to provide "a nationwide, robust, and integrated biosurveillance capability, with connections to international disease surveillance systems, in order to provide early warning and ongoing characterization of disease outbreaks in near real-time"(White House, 2008).

F. SIGNIFICANCE OF THE RESEARCH

Public health and medical information sharing has evolved greatly over the past decade. There has been a significant amount written in regard to the need for public health and medical information sharing, specifically biosurveillance, as a mechanism to increase situational awareness and common operating picture. In particular, the literature addresses the need for an integrated national biosurveillance enterprise. However, the literature is lacking a clear, detailed policy and roadmap for creation and implementation of a nationwide biosurveillance system. This research may serve as an initial roadmap for the implementation of an initiative to improve information sharing, including the

development of a national biosurveillance system through the integration of disparate systems, including systems that track human, animal, and plant health, as well as food recalls, weather, as well as the development of new systems. It will contribute data and analysis to a relatively new field of research. Additionally, it will justify the need for clearly defined leadership to drive the effort toward improved information sharing, as well as the development and enforcement of policies and an overarching strategy to improve information sharing. Ultimately, this will increase the level of health security and public health emergency preparedness of the United States against events of public health significance by facilitating near real-time situational awareness and common operating picture at all levels and jurisdictions. Officials in local, state, and federal public health agencies, government officials charged with emergency preparedness and response, and private sector healthcare institutions should find this research beneficial to their day-to-day disease surveillance and biosurveillance operations as well as their preparedness planning and response efforts for events of public health significance. Government officials charged with enhancing the nation's information sharing and biosurveillance capabilities should find this research advantageous in integrating existing systems. It will also be beneficial in developing an overall concept of operations and model for improving information sharing across jurisdictions and sectors to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture.

THIS PAGE INTENTIONALLY LEFT BLANK

II. RESEARCH METHODOLOGY

A qualitative analysis of case studies and interviews was conducted to address the research questions in this thesis. The overall premise of the research questions focuses upon how information sharing within the public health and medical enterprise can be improved to more rapidly detect and respond to intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture. Specifically, through the analysis of case studies and interviews, it examines current systems, how they are used and their limitations; barriers to information sharing; and what further actions may be taken to more rapidly detect and respond to outbreaks and to create better situational awareness and a common operating picture. Using an inductive approach, government reports, academic research, and advocacy group reports pertaining to the existing disease surveillance and biosurveillance systems were examined to identify strengths and weaknesses, existing gaps, and policies that limit the ability to provide near real-time situational awareness and common operating picture. Additionally, interviews of subject matter experts and officials in the field of biosurveillance were conducted. Based upon analysis of information contained within the case studies and from qualitative analysis of interviews, this study presents a conceptual model to improve information sharing within the public health and medical enterprise, which includes private sector partners, as well as, local, state, and federal government agencies.

A. SAMPLE/DATA COLLECTION

1. Case Studies

Case studies related to public health information sharing, including public health disease surveillance systems, syndromic surveillance systems, and biosurveillance systems from the United States and other countries throughout the world were selected to provide a broad overview of public health information-sharing initiatives.

The following case studies were selected:

- *Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States*
- *BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats*
- *Public Health Preparedness Informatics Infrastructure: A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*
- *Real-Time Biosurveillance Pilot in India and Sri Lanka*

The Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 U.S. States (Uscher-Pines et al., 2009) is a case study of health departments in eight states and their use of syndromic surveillance systems and associated protocols. This study describes current syndromic surveillance system response protocols and based upon the research findings makes a recommendation for a framework to guide initial design or enhancement of response protocols (Uscher-Pines et al., 2009).

The BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats (IOM & NRC, 2011) is a review and assessment of the effectiveness of the BioWatch program and the public health and healthcare system. This report provides the findings and conclusions of the Committee on Effectiveness of National Biosurveillance Systems regarding the merits of the BioWatch System and the public health and healthcare systems, the costs of each system, and recommendations for enhancements to strengthen the nation's biosurveillance capacity (IOM & NRC, 2011).

The Public Health Preparedness Informatics Infrastructure: A Case Study in Integrated Surveillance and Response: 2004–2005 National Influenza Vaccine Shortage (Gotham, Le, Sottolano, & Schmidt, 2008) looks at the advantages of an existing integrated informatics infrastructure for health information exchange in New York state. This report describes how the existing infrastructure provided a foundation for and improved the effectiveness of the response to the influenza vaccine shortage (Gotham et al., 2008).

The Real-Time Biosurveillance Pilot in India and Sri Lanka (Waidyanatha et al., 2010) is a case study of a pilot project that introduces modern biosurveillance technologies to health departments in India and Sri Lanka. It provides an overview of the technologies implemented and the initial findings regarding the usability of the systems (Waidyanatha et al., 2010).

2. Interviews

Subject matter experts and officials in the fields of disease surveillance and biosurveillance were interviewed. These individuals included an expert from academia who has published numerous articles pertaining to biosurveillance methodologies; two experts from the field of public health who are Career Epidemiology Field Officers; and a federal-level expert from the field of homeland security. These interviews provide the opportunity to gain first-hand knowledge of existing systems and initiatives related to public health/medical information sharing; barriers to information sharing within the existing systems; and how those systems, in conjunction with other actions, might be used to more rapidly detect and respond to outbreaks and to create better situational awareness and common operating picture. As with most qualitative research, the interview questions were open-ended so as to elicit the greatest amount of feedback from those who were interviewed.

Each interviewee was contacted by e-mail to provide background information on this project as well as to make the request for each to participate in the study. The interviewees were provided a copy of the interview questions. The interview questions were open-ended, so as to allow the respondent the most freedom to craft their response and provide optimum feedback. The interviewees' identities are protected and are not revealed in the thesis.

B. DATA ANALYSIS

Data from each case study was analyzed in a structured focused comparison. Elements to be analyzed are: existing systems for public health information sharing, disease surveillance, and biosurveillance; barriers to information sharing; uses and

potential uses for existing systems; and actions taken, including policy development and standards, to increase situational awareness and common operating picture.

An inductive, qualitative analysis of the interviews was conducted to identify themes, concepts and common thoughts on existing systems for public health information sharing, disease surveillance, and biosurveillance; barriers to information sharing; uses and potential uses for existing systems; and actions taken or future initiatives, including policy development and standards, to increase situational awareness and common operating picture. This thematic analysis forms the basis of the conclusions drawn from this study. For comparison purposes, the interview results were analyzed in tables using the same categories used for analysis of the case studies. However, the open-ended interview questions provided an abundance of information therefore additional categories are added to the interview analysis. The original categories along with the additional categories were used to identify themes, concepts, and common thoughts on existing systems for public health information sharing, disease surveillance, and biosurveillance; barriers to information sharing; uses and potential uses for existing systems; and actions taken or future initiatives, including policy and standard development, to increase situational awareness and common operating picture. Based on the interview data, analysis and conclusions, recommendations have been formulated on the development of a conceptual model to improve information sharing across jurisdictions and sectors to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture.

The goal of this research is to develop a conceptual model to improve information sharing within the public health and medical enterprise. The conceptual model developed is based upon the results from the analysis of the interviews conducted and the analysis of case studies related to public health information sharing, including public health disease surveillance systems, syndromic surveillance systems, and biosurveillance systems from the United States and other countries throughout the world. This proposed model could serve as an initial framework for the improvement of information sharing within the public health and medical enterprise, as well as the impetus for the development and implementation of an integrated national biosurveillance enterprise.

III. DISEASE SURVEILLANCE AND BIOSURVEILLANCE SYSTEMS CASE STUDIES

A. SYNDROMIC SURVEILLANCE CASE STUDY

After the events of September 11, 2001, many health departments began investing in syndromic surveillance technology. Syndromic surveillance includes "data sources such as nurse hotline calls, over-the-counter medication purchases, and chief complaints from emergency departments to monitor clusters of similar illness based on shared clinical presentation and in some cases tracking a single case of reportable disease" (Uscher-Pines et al., 2009). Syndromic surveillance systems have been "compared with a smoke detector that cannot serve its intended purpose without the timely public health response launched after aberration detection" (Uscher-Pines et al., 2009). Significant investments have been made in establishing syndromic surveillance systems and research on these systems has predominantly focused upon system performance and the comparison of detection algorithms. Few studies have specifically assessed the response protocols related to syndromic surveillance.

The *Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States* seeks to assess response protocols related to syndromic (Uscher-Pines et al., 2009) surveillance system alerts and the related guidance provided to public health practitioners. This case study consisted of: "semistructured interviews, textual analysis, and Delphi surveys" (Uscher-Pines et al., 2009). The goal of the interviews and surveys were to:

> …thoroughly describe response protocols for syndromic surveillance systems in place in 8 diverse states and their surrounding local public health departments, and to develop a framework for public health departments to use as a guide in initial design and/or enhancement of response protocols. (Uscher-Pines et al., 2009)

For the study, eight states out of 35 states with existing syndromic surveillance systems were selected from mutually exclusive categories (e.g., population size, locus of outbreak response) and based upon vulnerability to terrorist attack (Uscher-Pines et al., 2009). Participants for the semistructured interview process were selected by using three

approaches: contacting state epidemiologists requesting contact information for local health departments responsible for monitoring syndromic surveillance systems, snowball sampling (asking interviewees for additional contacts), and review of academic and gray literature for examples of health departments engaged in syndromic surveillance activities (Uscher-Pines et al., 2009).

To achieve the second goal, an expert panel was assembled. According to the authors, "two data sources were used to inform surveys of the expert panel: transcripts from the initial interviews with health department staff and text of response protocols" (Uscher-Pines et al., 2009). From these data sources, "a comprehensive list of response protocol elements for public health surveillance systems" was defined by the author (Institute of Medicine [IOM] and National Research Council [NRC], 2011). This panel participated in a two-round Delphi process. For the first round, the expert panel was provided with the initial comprehensive list of response protocol elements. The experts were asked to "comment on the completeness of the list and to add any additional elements" (IOM & NRC, 2011). For the second round of the Delphi process, participants received a questionnaire containing the elements chosen during round one and were asked to consider, "How important is it for a health department to include a given element in its written response protocol, given the resource constraints health departments typically face?" (Uscher-Pines et al., 2009).

The results for study objective one were divided into the following categories: description of systems; written protocols; uses of syndromic surveillance; regularity of monitoring; and investigation and notification (Uscher-Pines et al., 2009). Thirty health departments participated in the study; of those, 23 were active syndromic surveillance users. The study found that health departments monitored an average of 1.6 systems, including the Real-Time Outbreak and Disease Surveillance (RODS), BioSense, Electronic Surveillance System for the Early Notification of Community-Based Epidemics (ESSENCE), homegrown/unique systems, National Retail Data Monitor, First Watch, Early Aberration Reporting System (EARS), BioDefend, Syndrome Reporting Information System, RedBat, and Harvard-Pilgrim (Uscher-Pines et al., 2009). Eleven of the 23 health departments who were active syndromic surveillance users had written

response protocols; however, many had not been updated within the past 12 months. The study notes, "A consistent theme that emerged in interviews was the lack of a systematic process in designing protocols and few available informational resources or templates for response" (Uscher-Pines et al., 2009).

In the study, users noted the following to be the most common uses of syndromic surveillance: "to achieve situational awareness; to confirm, collaborate on, or rule out an event of significance; to support traditional epidemiological investigations (e.g., an investigation launched per the report of a clinician in the community who contacts the health department); to do targeted case finding; and to analyze trends" (Uscher-Pines et al., 2009). Other sorts of uses noted by interviewees included: identifying single cases of reportable disease that were not reported, as a decision making tool for issuing heat advisories, to rule out BioWatch alerts, and to "work backward" (Uscher-Pines et al., 2009).

The case study notes that the original purpose for syndromic surveillance was early warning or detection; however, no health department reported using the systems for that purpose. System monitoring was at least daily by most health departments, although some reported the inability to monitor after-hours or on weekends. Responses to alerts were classified into two categories: within-system[1] and beyond-systems[2] investigations (Uscher-Pines et al., 2009). Based upon interview responses, most alerts were subject to a within-systems investigation; however, health departments rarely conducted beyond-systems investigations. This is primarily due to the ability of the health departments to "rule out" suspicious alerts by checking for "causes of false positives within the system, limited resources to respond to every signal, and concerns about inconveniencing hospital staff" (Uscher-Pines et al., 2009).

Although interviewees noted written protocols that outlined notification policies, many had no actual experience in dealing with suspicious alerts or considered regular

[1] Within-systems investigations: "the data monitor only uses the tools available through syndromic surveillance or supportive biosurveillance systems"(Uscher-Pines et al., 2009)

[2] Beyond-systems investigations: "the monitor brings in additional resources such as hospital staff" (Uscher-Pines et al., 2009).

communication with community partners and internal staff to be sufficient. Respondents also noted reluctance to notify the State Department of Health because of lack of resources to support an investigation, lack of enthusiasm at the state level in regard to syndromic surveillance, and belief that events could be handled at the local level (Uscher-Pines et al., 2009). Additionally, respondents noted a lack of state coordination across regions or jurisdictions and no state oversight over multijurisdictional issues.

Study objective two included the review of existing written protocols; the compilation of a list of possible response protocol elements from interview transcripts and existing protocols; the assessment of the possible protocol list; and the rating of the necessity of identified written protocols. There were "thirty-two protocol elements identified within five distinct categories as essential elements according to expert consensus (essential elements are those that more than 50% of experts defined as essential, rather than desirable or not necessary)," they included: "description of system; monitoring policies; response procedures; role of syndromic surveillance response protocols within additional health department plans/protocols; and other" (Uscher-Pines et al., 2009).

The study found that the usefulness of syndromic surveillance systems "will be limited without the necessary infrastructure and methods to conduct an effective response and the active participation and cooperation of partners at the hospital level" (Uscher-Pines et al., 2009). Less than half of the surveyed health departments had written response protocols and the majority of those who had protocols had not updated them within 12 months. The absence of protocols was not regarded as a serious problem because health department personnel believed that response procedures were "understood and practiced" through daily communications between the community and public health partners (Uscher-Pines et al., 2009).

The study authors note one possible interpretation of the findings:

> …health department staff may question the need for written protocols because the focus of syndromic surveillance may be shifting away gradually from early warning and toward situational awareness (and most protocols are focused on alerts), and because specific instances in which

> syndromic surveillance first detected previously unknown events of public health significance have not often been identified. (Uscher-Pines et al., 2009)

There are instances, however, in which the authors note that written protocols are necessary, including: situations in which a health department is not in daily communication with local hospitals; when there are multiple system users with different monitoring responsibilities within one health department; instances where there is frequent staff turnover; and where there are complex jurisdictional issues concerning response (Uscher-Pines et al., 2009). Another reason to indicate that syndromic surveillance systems are used for situational awareness is the fact that "less than 15% of alerts were tracked in a beyond-systems investigation" (Uscher-Pines et al., 2009).

The second phase of this study allowed for the development of a generic framework for health department use. The expert panel who participated in the Delphi survey "emphasized elements related to interfacing with systems and communicating findings" (Uscher-Pines et al., 2009). The authors note that the framework developed in the study will allow health departments to "apply vetted response policies or enhance existing ones; furthermore having descriptions of the system(s), appropriate analyses, and investigation steps consolidated into a prototype comprehensive plan will provide material for training new staff" (Uscher-Pines et al., 2009). Furthermore, having standardized written protocols will support the integration of local jurisdiction outbreak response with regional, state, and national efforts.

Syndromic surveillance capabilities are tied to human resources for detection and response and achievement of actual preparedness. Health departments could benefit from the use of resources such as the guidance outlined in this study to build upon current response systems and improve their ability to "act upon—not merely detect—cases of, events of, and trends in public health significance" (Uscher-Pines et al., 2009).

B. INTEGRATED SURVEILLANCE AND RESPONSE CASE STUDY

The authors of Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004–2005 National Influenza Vaccine

Shortage state, "effective Public Health Emergency Preparedness (PHEP) requires integrated information systems supporting key PHEP activities including surveillance, alerting, situational awareness, emergency planning and response, resource assessment and management" (Gotham et al., 2008, p. 42). Having an informatics framework for health information exchange provides considerable advantages concerning advanced preparedness and just-in-time response to events of public health significance.

The Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004–2005 National Influenza Vaccine Shortage (Gotham et al., 2008) seeks to describe how an established health information exchange framework supported and enhanced the effectiveness of New York's response to the 2004 national influenza vaccine shortage.

In October 2004, production problems at Chiron, a major influenza vaccine manufacturer, cut the United States' supply of influenza vaccine in half. To compound issues, influenza vaccine was in high demand because of previous severe flu seasons. The response to this event "covered the spectrum of PHEP activities" (Gotham et al., 2008, p. 43). The CDC's plan to address the situation consisted of two phases: 1) release of limited vaccine orders, previously placed with alternate manufacturers, for providers and health care facilities according to estimates of risk group needs;" and 2) "state-wide orders for vaccine to meet priority risk group needs unmet by Phase I and other deliveries made prior to the shortage" (Gotham et al., 2008, p. 43).

In order to deal with the shortage, States activated their emergency response plans to:

1. Assess vaccine availability through previous orders and CDC Phase I
2. Assess unmet priority risk group vaccine needs across health care facilities, updating as the situation changed
3. Analyze and estimate vaccine to be ordered through CDC Phase II, updating as the situation evolved
4. Develop a statewide allocation and distribution plan for LHDs and health care facilities, based on the order placed with CDC, updating as the situation changed in the field (Gotham et al., 2008, p.43)

This endeavor, as noted by the authors, required prompt "communication, coordination, and assessment of needs and supplies across local health departments and health care facilities" (Gotham et al., 2008, p. 43).

The vaccine shortage occurred at the optimal time for influenza vaccination, leading to the possibility of increased influenza activity in the coming flu season. This required heightened surveillance for influenza cases as well as an increase in monitoring of health care resources (e.g., bed availability and emergency department visits). The study notes that "there was an absolute and urgent need for statewide situational awareness by decision makers across all information flows related to the event" (Gotham et al., 2008, p. 43).

Prior to the vaccine shortage, the New York State Department of Health (NYSDOH) had developed an "informatics framework and strategic information infrastructure to support information exchange with its health information trading partners" (Gotham et al., 2008, p. 44). This secure, web-enabled portal, Health Commerce System (HCS), supports the information exchange between all regulated health entities in New York. The HCS supports a wide range of health-related activities, to include "vital records, health care quality assurance and finance, disease registry and condition reporting, statewide communicable disease and laboratory reporting, arbovirus surveillance, child health insurance reporting, managed care, even prescription pad orders" (Gotham et al., 2008, p. 44). This infrastructure is well suited for public health emergency response because of its existing architecture and routine use by response partners. It is an "integral component of the NYSDOH incident management system and PHEP plans" and has supported statewide responses to "emergent infectious disease events, emergency disaster declarations, health resource shortages, elevated national threat levels, and high-profile security events" (Gotham et al., 2008, p. 45).

The study notes that the HCS system was in operation prior to the vaccine shortage and had been used in preparedness exercises and other PHEP events prior to 2004. Specific systems that supported the NYSDOH response to the 2004 influenza

vaccine shortage were: the Hospital Emergency Response Data System (HERDS), the Integrated Health Alerting and Notification System (IHANS), and the dashboard-secure collaboration form (Gotham et al., 2008, p. 47).

The HERDS system is used by all hospitals, local health departments, nursing homes, adult- and home-care entities, and schools. It was routinely used by hospitals at the time of the vaccine shortage and prototypes were deployed to local health departments and nursing homes. In response to the vaccine shortage, the HERDS system was used for ongoing monitoring of bed availability and hospital emergency department visits, as well as a statewide hospital-based surveillance system for pediatric influenza (Gotham et al., 2008, p. 47). During the shortage, the NYSDOH used HERDS to deploy a vaccine inventory survey to all hospitals. The study discusses the fact that just prior to the influenza vaccine shortage, the HERDs system was used to conduct a statewide survey of hospital critical assets in preparation for the 2004 Republican National Convention. The information collected in that survey proved beneficial to resource allocation and response activities related to the vaccine shortage.

In order to respond to the vaccine shortage, the NYSDOH needed to:

> 1) assess and update data on vaccine inventories, orders, and needs for priority risk groups in the state; 2) develop ordering requirements for CDC Phase II; 3) develop an in-state allocation and distribution plan based on up-to-the-minute data; 4) assure rapid and effective communication with LHDs and health facilities; 5) monitor the effects of increased influenza activity or hospital utilization due to vaccination shortfalls; 6) detect local increases in influenza activity; 7) assure overall situational awareness for NYSDOH executive incident command process and for external response partners. (Gotham et al., 2008, p. 48)

Through the use of HERDS, the NYSDOH completed and continuously updated a statewide needs assessment across hospitals and healthcare facilities. Data collection from facilities not using HERDS was “laborious and time consuming” (Gotham et al., 2008, p. 48). The data collected via HERDS allowed the NYSDOH to rapidly develop a data-driven vaccine allocation plan for the state. The HERDS system also allowed for tracking and trending of emergency department visits, including the ability to monitor, verify, and discount indications of anecdotal reports of emergency department or hospital

overcrowding. Having the surveillance process for pediatric influenza in place allowed for the expansion to inclusion of laboratory-confirmed influenza for all age groups. The authors note that this "greatly facilitated the reporting process and also provided an integral location for reviewing reporting streams" (Gotham et al., 2008, p. 51). The authors go on to state:

> The IHANS alerting system served four roles in NY's efforts to provide situational awareness to external response partners: supporting advance preparedness; directly providing event-related content; notifying partners of the availability of new (or updates to) analytic products on the dashboard system; and notifying both organizations and health officials that HERDS surveys had been activated. (Gotham et al., 2008, p. 51)

The IHANS system provided alerts in advance of the shortage encouraging hospitals to prepare for an increase in influenza activity and preparedness recommendations, including vaccination recommendations, shortage updates, response plans for the state and federal level, influenza activity updates, priority group recommendations, and peripheral impacts of the shortage.

The collaboration dashboard forum provided situational awareness for external partners through reports, charts, and graphs developed from data in the HCS data system. The dashboard allowed external response partners "to access information related to vaccine needs across facility types, vaccine shipments, and allocations within jurisdiction" (Gotham et al., 2008, p. 53). Additionally, customized HERDS data feeds were provided through the collaboration dashboard.

This study concluded, "The presence of an established integrated informatics framework for health information exchange and PHEP in New York State conveyed significant advantages in advanced preparedness and just-in-time response to this health event" (Gotham et al., 2008, p. 53). The benefits of having such a framework are:

> …a demonstrable state of response readiness; rapid establishment and maintenance of situational awareness across response partners through just-in-time dynamic information-gathering activities; effective communication and coordination of a broad spectrum of response activities; rapid development and implementation of data-driven response plan." (Gotham et al., 2008, p. 53)

The authors cite specific lessons learned, including: having an established, dual-use informatics framework optimizes readiness; advantages to the system, such as, economy of scale, familiarity, common and standardized usability, depth and breadth of partner inclusion and communication; data integration; and new opportunities for linkages; systems like HERDS are ideally suited to emergent PHEP events because they support rapid, integrated, and flexible deployment of surveys; and involvement of all types of health care organizations in information sharing speeds the processing of survey and surveillance data (Gotham et al., 2008, p. 54).

C. AIR SAMPLING AND PUBLIC HEALTH SURVEILLANCE CASE STUDY

In response to the threats of a naturally emerging or re-emerging infectious disease and bioterrorism, the United States and many other countries "have been actively seeking means to improve capabilities to detect and respond to biological threats" (IOM & NRC, 2011, p. xi). In an effort to improve the detection of aerosolized biological agents, the United States Department of Homeland Security (DHS) developed and rapidly deployed the BioWatch program. This program is an "environmental monitoring system intended to speed detection of specific aerosolized biological agents," consisting of air sampling devices "deployed, primarily in outdoor locations, in more than 30 major urban areas" (IOM & NRC, 2011, p. 2).

The BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version examines, "the BioWatch program and its costs and merits in relation to methods for disease surveillance through the public health and health care systems" (IOM & NRC, 2011, p. 1). In addition to the evaluation, it describes "characteristics of an 'enhanced national surveillance system' that relies on U.S. hospitals and the U.S. public health system;" examines "the costs, merits, and capabilities of the current and potential 'enhanced national surveillance system' to provide a basis for a rapid response to bioterrorist attacks or other biothreats, including initiation of pre-infection prophylaxis and expedited response and recovery;" and reaches "a conclusion as to whether the two systems are redundant or complementary, both in current configuration and potential 'enhanced' configuration" (IOM & NRC, 2011, p. 4).

BioWatch is a federal program, operated by DHS, which relies upon the collaboration with other federal partners, as well as states and localities where the BioWatch system is deployed. Because it relies upon the state or local public health system to interpret and respond to BioWatch Actionable Results (BARs), it is necessary for it to have an effective relationship with the public health system in the locations where it is deployed. The study notes that "health care providers, laboratories, and health departments work together to diagnose disease and recognize outbreaks that require a broader response than standard treatment provided for individual, unrelated cases" (IOM & NRC, 2011, p. 25). The intent of the BioWatch system is to provide "earlier warning to health departments of the aerosolized release of certain bioterrorism agents so that a rapid response can limit morbidity and mortality" (IOM & NRC, 2011, p. 25).

The public health and healthcare system are highly decentralized and have very loose connections. According to the authors of this study, "neither in public health nor in health care is there an overarching national mechanism for unifying or coordinating the disparate, and often competing, entities involved" (IOM & NRC, 2011, p. 29). The public health system relies upon private physicians and hospitals to report diseases and illnesses for early detection and response. The authors of this study state "without an effective response capability, good surveillance and detection alone can contribute very little to limiting morbidity and mortality" (IOM & NRC, 2011, p. 30). If a BAR is detected, the BioWatch system relies upon the public health system to take prompt action, such as implementing a prophylaxis campaign. The study notes that the public health and health care system's confidence in the BioWatch system is critical to success.

The authors note that public health systems have made significant investments in novel and promising surveillance techniques and programs, due in part from funding for bioterrorism and public health emergency preparedness. Despite these investments, the authors identified some shortcomings, including: insufficient evidence of the utility of novel surveillance techniques; uneven distribution of surveillance capacities; incomplete development and uneven implementation of national surveillance standards; inadequate attention to useful methods for "linking integrating, analyzing, and displaying multiple surveillance platforms for optimal situational awareness, decision making, and response;"

and year-to-year federal funding that prevents program planning and deters personnel recruitment (IOM & NRC, 2011, p. 91). In addition, the study notes that there are numerous surveillance systems and databases, which have been created in a piecemeal fashion over time for tracking specific diseases and conditions or for other purposes. "Integrating these across local and state levels would permit greater awareness of patterns and trends and increase the likelihood that anomalies" are detected and investigated (IOM & NRC, 2011, p. 105).

Public health and health care systems have been the focus of numerous studies, task forces, and commissions. From these activities, broad themes have emerged and are noted in this report. Some of these themes are: surveillance information sharing needs to be improved between the health care system and state and local public health agencies; improvement is needed in automated systems used to improve the sharing of surveillance information between the health care system and state and local public health agencies; and human health information integration with surveillance of animal disease and air and water quality—"biosurveillance" (IOM & NRC, 2011, 97).

The fundamental question, as identified in this study is "whether BioWatch can perform in a useful way." There have been instances where samples from the BioWatch system have produced positive findings that were identified as being genetic material from an organism among those currently being monitored. This has demonstrated that the technology can collect "analyzable genetic material and that the current laboratory assays can detect this genetic material" (IOM & NRC, 2011, p. 125). However, through the use of traditional surveillance systems, the jurisdictions determined that there had not been a terrorist release and there was no indication of increased illness in humans.

The study committee notes that it "is most confident about the potential for early detection via BioWatch to reduce morbidity or mortality in the event of a massive aerosol attack using Bacillus (B.) anthracis spores, assuming an effective public health response capability is in place" (IOM & NRC, 2011, p. 127). The study goes on to note that although there may be a BAR, "it does not automatically trigger a public health response" (IOM & NRC, 2011, p. 128). The public health response will depend upon the public health officials' interpretation of available traditional surveillance data, the number of

BioWatch collectors generating positive results, and follow-up environmental sampling. BioWatch is a "narrowly focused" detection tool, "it does not eliminate the need for the broad-based surveillance activities that can detect bioterrorism or naturally occurring disease outbreaks that BioWatch (enhanced or not) cannot or does not detect" (IOM & NRC, 2011, p. 138). Traditional public health and health care system surveillance and BioWatch are complementary.

Finally, the study notes, "Although the deployment of the BioWatch system has been somewhat rocky in terms of coordination and integration with local public health officials, there is a continuing national effort to achieve a more integrated system from the multitude of local and state systems for infectious disease surveillance" (IOM & NRC, 2011, p. 143). The study notes that the integration of the BioWatch system into local surveillance systems, which are integrated into a representative national biosurveillance system, will increase the sustainability and effectiveness of the BioWatch program.

D. DISEASE SURVEILLANCE IN INDIA AND SRI LANKA AND A REAL-TIME BIOSURVEILLANCE PILOT PROJECT

The International Health Regulations (IHR) (2005) adopted by the World Health Organization (WHO) makes it compulsory for member states to meet certain requirements and comply with the provisions of the regulation to enhance national, regional, and global public health security (Kant & Krishnan, 2010). With India and Sri Lanka both being member states of the WHO, they are obligated to have plans of action to develop and implement the necessary capabilities to comply with the IHR 2005, including the capacity for public health surveillance and response (World Health Organization, 2008).

Both India and Sri Lanka have been working to establish, implement, and operate a disease surveillance program, including a biosurveillance program, which meets the requirements of the IHR 2005. Both countries have made significant progress in establishing traditional disease surveillance systems and biosurveillance systems.

1. India

India's constitution provides autonomy to the 28 states within the country. One of the responsibilities falling under the state's purview is health. Because of this system, disease surveillance development and progress throughout India has been varied, with a "large number of disease control programmes [sic], each with its own system of data gathering. Historically, these have been vertical programmes [sic]" (Kant & Krishnan, 2010). India conducts surveillance on "vector borne infections, diarrhoeal [sic] diseases, respiratory diseases, and vaccine preventable diseases," as well as unusual occurrences that may indicate the use of a biological agent (Kant & Krishnan, 2010).

In 2004, India launched the Integrated Disease Surveillance Project in an attempt to bring the disparate disease control programs and data systems into an integrated system. Through this program, India integrated and decentralized its disease surveillance activities by establishing surveillance units at the district, state, and national level (Kant & Krishnan, 2010).

This system is predominantly a paper-based system where reports are collected on a weekly basis from sub-centers, primary health centers, community health centers, hospitals, and laboratories. These paper reports are received by data managers, who enter the data into a Web-based portal where it can be analyzed and disseminated (Kant & Krishnan, 2010). Approximately 850,000 sub-centers and approximately 150,000 primary health centers, community health centers, and hospitals submit weekly reports on syndromes and cases (Kant & Krishnan, 2010). In addition to traditional surveillance, India has a Media Scanning and Verification Cell at the National Centre for Disease Control in New Dehli. According to the study, "This cell collates reported unusual health events on infectious diseases within the country and informs the concerned state, district, and national level health officials" (Kant & Krishnan, 2010). Once identified, these occurrences are investigated and verified, and communicated to the appropriate authorities for further action. Media scanning increases the sensitivity of India's official surveillance system and has the potential to provide early warning of new disease clusters, prior to an official identification and notification.

India has made great strides in developing and implementing the infrastructure for an integrated disease surveillance and biosurveillance system. However, there are areas that still need to be addressed, encouraging private sector reporting, integrating the disease surveillance technology with other health programs, improving the media scanning and verification process, and having all-inclusive data transmission by including mobile, text, voice, e-mail, and fax capabilities (Kant & Krishnan, 2010).

2. Sri Lanka

Sri Lanka is broken into provinces, districts, and local governments consisting of municipal councils, urban councils, and *Pradeshiya Sabhas* (divisional/rural councils) (United Nations Economic and Social Commission for Asia and the Pacific, n.d.). Promoting public health is a function of the local government.

The philosophy and underpinnings of the Sri Lankan disease surveillance system dates back to the "Quarantine and Prevention of Diseases Ordinance" introduced by the British in 1897 (Waidyanatha, 2010). It is limited to a handful of notifiable diseases, which physicians in the country are required by law to report to public health officials. The disease reporting system is predominantly a paper based system with data analysis being done at the national level. There are 270 Medical Officers of Health (MOH) in Sri Lanka to whom physicians and hospitals report. Public Health Investigators (PHI) in the area will conduct an investigation to either confirm or refute the disease. On a weekly basis, the MOH will complete a weekly return of communicable disease (WRCD) and send it to the Epidemiological Unit at the Ministry of Health and a copy to the Regional Epidemiologist (Epidemiology Unit, Ministry of Health, 2005).

In Sri Lanka, there are "separate vertical programmes [sic] to control and monitor malaria, filariasis, leprosy, respiratory diseases, human rabies, cancer, HIV/AIDS and STDs" (Regional Office for South-East Asia, 2003). These systems, along with systems for specialized disease surveillance operate separately and the data collected within these systems is not integrated.

Sri Lanka has implemented an early warning system to more rapidly identify outbreaks of disease so that control measures might be instituted immediately. In

addition to routine reporting of notifiable diseases, Sri Lanka uses: "sentinel surveillance; entomological surveillance; news reports and rumour [sic] reports; as well as web postings and e-mail alerts" (Regional Office for South-east Asia, 2004).

Sri Lanka has a robust disease surveillance system, however, those systems are not integrated and do not collect information from outpatient departments and clinics, as well as the private sector (Regional Office for South-east Asia, 2004). The potential exists for the existing system to be made even stronger by including new data collection sources and methodologies and integrating the many vertical disease specific surveillance programs, and surveillance for specialized campaigns.

3. Real-Time Biosurveillance Program in India and Sri Lanka

The predominantly paper based systems for disease reporting in both India and Sri Lanka prohibits timely detection of disease outbreaks and limits the ability of the health systems in these countries to effectively respond to and mitigate the disease consequences. In an effort to address this issue, the Real-Time Biosurveillance Program (RTBP) was pilot tested in Tamil Nadu, India, and Sri Lanka. This pilot was an effort to bring "modern technology to health departments" to "complement the existing disease surveillance and notification systems" (Waidyanatha et al., 2010).

The pilot included "digitizing all clinical health records and analyzing them in near real-time to detect unusual events" (Waidyanatha et al., 2010). A mobile phone application (m-Health Survey) was used to collect patient demographic information, disease, or syndrome. The collected information was transmitted to the "T-Cube Web Interface" (TCWI), a Web-based software product using the T-Cube data structure (Waidyanatha et al., 2010). This interface allows for quick retrieval, analysis, and display of the collected data. The pilot also included the "Sahana Messaging/Alerting Module," which was used to disseminate information regarding detected adverse events to health officials and workers via SMS, e-mail, and Web (Waidyanatha et al., 2010). The alerting module is based upon the Centers for Disease Control and Prevention's Public Health Information Network (PHIN) Communication and Alerting Guide (PCA),

which provides a "comprehensive set of alerting attributes using Common Alerting Protocol (CAP) and Emergency Data Exchange Language" (Waidyanatha et al., 2010).

The RTBP pilot provided health officials in India and Sri Lanka the ability to "detect and monitor a wide variety of health events, involving multiple kinds of diseases, including communicable and non-communicable, as well as reportable and non-reportable diseases" (Waidyanatha et al., 2010). The overall project proved that mobile phone technology (m-Health Survey) is an efficient mechanism for near real-time collecting and reporting of disease surveillance data, the T-Cube Web Interface (TCWI) was effective for near real-time outbreak detection, and the Sahana Alerting Module was effective for the dissemination of real-time health risk information (Waidyanatha et al., 2010). Preliminary lessons from the pilot were: 1) "the need for more robust mobile application for data collection with complete standardized content in disease-syndrome" and 2) "more rigorous capacity building and frequent use is required for health officials to take advantage of the full potential of TCWI" (Waidyanatha et al., 2010).

E. THEORETICAL SENSITIVITY

Leedy and Ormrod state:

> Qualitative researchers believe that the researcher's ability to interpret and make sense of what he or she sees is critical for understanding any social phenomenon. In this sense, the researcher is an instrument, in much the same way that a sociogram, rating scale, or intelligence test is an instrument. (Leedy & Ormrod, 2005, p. 133)

Since the author is the instrument in this thesis, it is important to understand the origins of her "theoretical sensitivity."

"Theoretical sensitivity" as described by Glaser and Strauss (1967) and Strauss and Corbin (1990) is "a personal quality of the researcher" (Strauss & Corbin, 1990, p. 42). This concept is useful when evaluating a researcher's skill and readiness to conduct qualitative research. Specifically, "it refers to the attribute of having insight, the ability to give meaning to data, the capacity to understand, and the capability to separate the pertinent from that which is not" (Strauss & Corbin, 1990, p. 42). Strauss and Corbin go further to outline sources of theoretical sensitivity, including professional experiences,

personal experiences, and review of professional literature. Experience, such as this, lends credibility to the researcher and gives the readers confidence in the researcher's ability to be sensitive to the data and to make appropriate interpretations and decisions during analysis. To characterize the author's credibility, her experiences are detailed below.

The author has spent her entire professional career, working in some capacity with public health surveillance systems. She has worked with a federal-level hospital surveillance system and local level public health surveillance systems, specifically in regard to infectious diseases. The author is an epidemiologist at a regional health department, where she has worked for approximately nine years. A portion of her duties involve infectious disease surveillance, investigation, and reporting. Additionally, the author worked as a contract public health analyst at the Centers for Disease Control and Prevention, where her job duties were related to program management, development, and implementation of segments of a national, voluntary, Web-based hospital surveillance program. Experiences from work in both of these capacities have shaped the author's ideas and beliefs relative to disease surveillance at the organizational, local, state, and federal levels.

Most specifically, the author's work as an epidemiologist at a regional health department has given her ample opportunity to develop opinions and theories related to disease surveillance and biosurveillance. Involvement in local infectious and non-infectious disease outbreaks as well as those with links to state-wide and national outbreaks has helped to shape her theories and opinions in relation to disease surveillance capabilities and the need for an integrated national biosurveillance enterprise. Research and the review of relevant literature continue to shape the author's views of current public health surveillance and biosurveillance activities, its shortcomings, and the way to the future.

Daily work within the public health system, as well as contact with the private sector, including hospitals, private physicians, and laboratories, has provided the author with the unique experience to observe the current uses and limitations of disease surveillance and biosurveillance systems. She has encountered many barriers to

information sharing, which will be discussed in this research. She is intimately familiar with the current uses of local public health surveillance systems, and through research and interviews, has become much more aware of national level public health surveillance and biosurveillance systems. Through work experience and research, the author has formulated and identified many future actions that should be undertaken in order to address the shortfalls of existing public health surveillance and biosurveillance systems.

The authors state, "In a qualitative study, the interpretation of the data will inevitably be influenced by the researcher's biases and values" (Leedy & Ormrod, 2005, p. 151). Leedy and Ormrod urge the researcher to "minimize the extent to which your prior expectations and opinions enter" into the final analysis by collecting "two or more different kinds of data" related to the subject (Leedy & Ormrod, 2005, p. 151). The author includes both case studies and interviews in the research to ensure an adequate and complete analysis related to public health surveillance and biosurveillance capabilities and capacities, as well as the need to improve information sharing and for the development of an integrated national biosurveillance system. Case studies related to various types of public health and biosurveillance systems were selected, along with professionals from various fields who are stakeholders. This allows for exposure to alternative opinions and beliefs and broadens the author's view of the concepts, issues, and challenges. Furthermore, during the analysis of the case studies and interviews, the author made a concerted effort to maintain awareness of her theoretical sensitivities through continued reflection upon the data and her analysis of the data, by continually questioning what is happening here. What is the data really saying? What biases may be entering into the analysis? This introspective approach is vitally important to retaining objectivity in the research, decreasing bias, and conducting a straightforward analysis.

F. ANALYSIS

Each of these case studies describes different technologies that are used for information sharing to conduct basic disease surveillance, biosurveillance, and to provide situational awareness and/or common operating picture. There are varying levels of information sharing between and among the systems that are presently in use, some

systems have many connections whereas others do not. Each system is successful in its own right and has some merit for outbreak detection and situational awareness and common operating picture.

Most of the systems reviewed in the case studies provide situational awareness but do not facilitate a common operating picture, as evidenced by Table 1. This table provides an overview of the systems discussed in each case study and whether it provides situational awareness, common operating picture, or both. Of those systems that do provide for a common operating picture, it is limited to those who are users or contributors to the systems themselves and does not provide a common operating picture for those outside the system. The systems provide a wide range of information from over-the-counter medication sales to air monitoring data to traditional disease surveillance. The system described by Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004–2005 National Influenza Vaccine Shortage is a small-scale example of a healthcare/public health centric integrated system approach to information sharing for situational awareness and common operating picture (Gotham et al., 2008). This system could serve as a model for the initial development and deployment of an integrated national biosurveillance system.

Table 1. Current Systems and the Provision of Situational Awareness or Common Operating Picture

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	***Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage***	***BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version***	***Real-time Biosurveillance Pilot Program in India and Sri Lanka***
Situational Awareness	• Syndromic Surveillance • Real-Time Outbreak and Disease Surveillance • BioSense • Electronic Surveillance System for the Early Notification of Community-based Epidemics (ESSENCE) • Homegrown/Unique Syndromic Surveillance Systems • National Retail Data Monitor (NRDM) • First Watch	• Health Commerce System (Health Information Exchange • HERDS (Health Emergency Response Data System • CDESS (Communicable Disease Electronic Surveillance System) • IHANS (Integrated Health Alerting and	• BioWatch • Biohazard Detection System (BDS) • DoD Indoor Air monitoring • Joint Biological Standoff Detection System	• M-Health Survey • T-cube Web Interface • Sahana Messaging/Alerting Module

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	***Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage***	***BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version***	***Real-time Biosurveillance Pilot Program in India and Sri Lanka***
	• Early Aberration Reporting system (EARS) • Bio-Defend • Syndrome Reporting Information System • RedBat • Harvard-Pilgrim	Notification System) • ComDir (Communications Directory) • ECLRS (Electronic clinical Laboratory Reporting System) • EDB (Executive Dashboard) • Event Website • Secure File Viewer and Collaboration Dashboard System		
Common Operating	• BioSense • FirstWatch	• Health Commerce		

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
Picture		System (Health Information Exchange) • HERDS (Health Emergency Response Data System) • EDB (Executive Dashboard) • Event Website • Secure File Viewer and Collaboration Dashboard System		

Patterns emerge when looking at the limitations of the existing systems. Table 2 identifies the limitations of the existing systems as outlined in the case studies. Most of the limitations to the current systems revolve around systemic issues—the infrastructure, or lack thereof; the lack of standard processes and procedures; lack of resources; lack of

collaboration and coordination; and a lack of ability to fully use the systems due to lack of training or familiarity. There is still reliance upon paper-based systems and a reluctance to move away from that process, as identified in some of the case studies. The case studies also identify issues with improvement efforts, which ultimately create problems in other areas within the systems. These are issues that are common to the entire public health and biosurveillance enterprise.

Issues identified by three of the four case studies are the detection capability, alert validity, response, and tracking of cases. These issues can have a significant impact upon the overall success of a biosurveillance system. If the system is not sensitive enough to detect anomalies or the validity of anomaly detection is in question, the system does not provide the user with the necessary information to respond to events of public health significance. Nor does it provide a useful mechanism to track cases.

Table 2. Limitations of Current Systems

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	***Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage***	***BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version***	***Real-time Biosurveillance Pilot Program in India and Sri Lanka***
Utility of existing systems is limited without necessary infrastructure and methods to conduct a response	*X*		*X*	
Partner participation and collaboration	*X*		*X*	
Lack of familiarity or experience with system				*X*
Lack of collaboration and connection with traditional public health surveillance systems			*X*	

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
Decreased analytic capabilities due to data inconsistencies and efforts to reduce "noise"				*X*
Detection capability, alert validity, response, and tracking	*X*		*X*	*X*
Intended for early warning/detection but not used for that purpose	*X*			

Table 3 provides a glimpse of the existing barriers to information sharing, which inhibits the ability to maintain situational awareness and common operating picture. The issues identified are similar to those cited as limitations, including: lack of collaboration; resistance to the systems; lack of knowledge and familiarity with the system; governance issues; and organizational and resource issues. These are common barriers to information sharing within any discipline. The barrier identified in all four case studies is "Scientific

and Technical Hurdles." For public health surveillance and biosurveillance systems to be successful, the users must be familiar with the system and comfortable using it. Additionally, the system must generate accurate and useful information, which can be applied to the current situation for decision making. The systems must keep false positives to a minimum, as these may desensitize the user to future alerts. Most importantly, the system must be efficient; data entry cannot be time consuming as this is a deterrent to use. These obstacles are not impossible to overcome; however, they might be the most important. Without a strong governance structure, collaboration, knowledge, and resources, achieving an integrated national biosurveillance enterprise will be difficult.

Table 3. Barriers to Information Sharing

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	***Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage***	***BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version***	***Real-time Biosurveillance Pilot Program in India and Sri Lanka***
No response protocols for events in multiple jurisdictions	*X*			
No registry of users	*X*			
Lack of implementation and coordination across organizations/jurisdictions/regions	*X*		*X*	

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
Scientific and technical hurdles: lack of knowledge of the system, laborious and time consuming data collection, false-positive alerts	*X*	*X*	*X*	*X*
Resistance, organizational, and financial obstacles	*X*		*X*	

Although the systems identified in the case studies are used for a variety of purposes, the desired end results are detection, mitigation, and prevention of disease or illness. Table 4 identifies the ways that disease surveillance and biosurveillance systems in the case studies are used. Functions of the systems ranged from providing analysis, visualization, and reporting to early detection and traditional disease surveillance and case tracking and follow-up. Novel uses included administering surveys to existing users to provide data for decision making, as well as alerting and situation reporting. The uses outlined in the case studies are reflective of the use of existing systems within the public health and biosurveillance enterprise.

Table 4. Uses of Current Systems

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
Early outbreak detection	*X*	*X*	*X*	*X*
Single case-finding and tracking	*X*			*X*
Timely health response	*X*		*X*	*X*
Situational awareness	*X*	*X*	*X*	*X*
Identify, confirm, collaborate on, or rule out an event of significance	*X*	*X*		*X*
Support traditional epidemiological investigations and surveillance activities	*X*	*X*		*X*

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
Tool for analysis, manipulation, and visualization of datasets and anomaly detection	*X*			*X*
Detection of infectious diseases, emerging infectious diseases, and non-communicable diseases		*X*		*X*
Decision-making tool for planning and response, resource management,	*X*	*X*	*X*	*X*

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
and efforts to mitigate health effects				
Facility-specific reporting and situational awareness		*X*		
Administration, collection and analysis of survey data		*X*		*X*

The current systems are used for a wide variety of purposes; however numerous further actions or steps can be taken to improve the existing systems. Table 5 outlines further actions needed to improve the systems, as outlined in the case studies. The primary themes, which emerge are the need for evaluation and testing; protocols; daily use of the systems; coordination and integration; and resource availability and a competent workforce. Many of the issues for further action address the systemic issues identified in the case studies. Systemic issues are often difficult to change because it requires fundamental changes to the existing philosophies and culture within a system.

Standardization of the evaluation and response protocols are important if an integrated national biosurveillance system is the desired end result. Having standards

allows for disparate systems to be integrated so that data can be compared to create situational awareness and common operating picture. Additionally, having a trained cadre of professionals using the systems increases the reliability and validity of the outputs, thereby improving the overall situational awareness and common operating picture generated by the system.

Table 5. Further Actions to Improve Systems

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
Development of a standardized evaluation and response framework, including standardized content for disease-syndrome, to assist in integration of systems at the regional, state, and national levels	*X*		*X*	*X*
Require organizations to build and sustain a cadre of trained individuals	*X*	*X*	*X*	

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
through training on syndromic surveillance and its benefits				
Build capacity and establish the system as a common practice through routine use		*X*		*X*
Better involvement, coordination and collaboration of stakeholders public health systems and healthcare organizations in Preparedness Systems		*X*	*X*	

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
Integrate components into a stronger, nationally coordinated public health surveillance and biosurveillance framework			*X*	
Develop and evaluate, through testing and exercises, new technologies with the capability to interpret and respond to infectious disease events			*X*	*X*
Develop mechanisms for		*X*	*X*	*X*

	Framework for the Development of Response Protocols for Public Health Syndromic Surveillance Systems: Case Studies of 8 US States	*Public Health Preparedness Informatics Infrastructure. A Case Study in Integrated Surveillance and Response: 2004-2005 National Influenza Vaccine Shortage*	*BioWatch and Public Health Surveillance: Evaluating Systems for the Early Detection of Biological Threats: Abbreviated Version*	*Real-time Biosurveillance Pilot Program in India and Sri Lanka*
improving situational awareness, including information sharing				

These case studies describe successful information sharing across jurisdictions and sectors, at times for rapid detection, but more often to provide varying levels of situational awareness and common operating picture. However, they note that there are barriers to information sharing and that there is room for improvement in disease surveillance and biosurveillance systems that currently exist. Recommendations include standardization of systems and protocols, training, collaboration, coordination, and information sharing. Each system relies upon connections to other systems and stakeholders in order to achieve the highest level of situational awareness and common operating picture. This reinforces the idea that integration is necessary for more rapid detection of naturally occurring or intentional disease outbreaks and to create better situational awareness and common operating picture.

IV. INTERVIEWS AND ANALYSIS

Interviews of experts in the field of public health and biosurveillance were conducted. These experts practice in the fields of academia, public health, and homeland security. Each interviewee had a different professional background; however, they have experience with public health surveillance and biosurveillance in some capacity. Tables are used to provide a mechanism for easy visualization and comparison of the interview responses. The tables do not represent specific questions and the responses to those questions; rather they represent overarching themes that emerged during the interview process. The interview questions were to serve as merely a guide to the discussion. The analysis of these interview responses resulted in similar themes emerging, as can be seen in the following tables and accompanying analysis.

The open-ended nature of the interview questions afforded ample opportunity for discussion related to the health and medical enterprise and information sharing. The initial discussion revolved around existing systems and how they were used. As evidenced in Table 6, there are a multitude of systems at the local, state, and federal level with various missions. They range from traditional disease surveillance activities to early detection and notification or communication. Each interviewee had different experiences with various systems, as illustrated in Table 6. The interviewees stated there was no way to discuss or even mention the majority of the systems as there were far too many, each with a distinct purpose and function. This in and of itself is part of the challenge associated with information sharing and with creating an integrated national biosurveillance system—there are so many systems that exist and serve a variety of functions, all operated by different entities, who are not always willing to share information with others for various reasons.

A. CURRENT SYSTEMS AND THEIR USE

The majority of the systems today function as traditional disease surveillance and reporting systems. As noted by both the public health and homeland security professionals, Health and Human Services and the Centers for Disease Control and

Prevention have numerous systems that function in the traditional disease surveillance capacity, as well as some form of biosurveillance. Most of the systems listed below (Table 6) are local, state, or federal systems that exist independently and have a single mission, although, systems such as BioSense and Fluview have more of a biosurveillance focus. After the events of 9/11, early detection, biosurveillance, and the need for integration of response and information sharing became significant. The use of the Incident Command System within the public health and medical arena is a relatively new phenomenon but has been successful in integrating the public health and medical enterprise response with traditional first response agencies. It has facilitated and improved information sharing between all agencies involved.

Table 6. Current Systems and Their Use

	Public Health	Academia	Homeland Security
For integration of response and information sharing	• Incident Command System		
Laboratory surveillance	• PulseNet		
Notification and communication	• Epi-X—subscriber based • CDC HAN (Health Alert Network)—broadcast messages to subscribers		
Early detection		• Early Aberration Reporting System (EARS)—free platform	• Poison Control Center
Situational awareness	• Syndromic Surveillance	• Early Aberration Reporting System	• Open-source monitoring—world-

	Public Health	Academia	Homeland Security
	• FluView	(EARS)—free platform • Bio Sense—limited to specific geographic areas, not all encompassing	wide, all domains of interest looking for biological events • Syndromic Surveillance • Poison Control Center
General disease surveillance and/or some form of biosurveillance	• CDC has numerous systems that evolved independently and on their own timeframe		• National Biosurveillance Integration Center—received high-level reports from other agencies, no data access • Health and Human Services has numerous systems in place for disease surveillance

B. LIMITATIONS

The discussion of current systems and their use initiated a discussion of the limitations of current systems (Table 7). Common themes emerged, as many of the limitations were identified by each of the professional groups interviewed. The primary issues cited during the interviews centered on the numerous systems, which gather a variety of data; the lack of overall guidance and standards for those systems and their development; and the absence of integration of the information from the various systems. Furthermore, the interviewees discussed the fact that many of our systems are balkanized, still collecting data, and communicating on paper. The existing systems, including syndromic surveillance systems were developed with little forethought and planning and have no standards related to the systems, analysis, or reporting of the data. The public

health interviewees also noted the fact that there is currently no common operating picture where all information can be visualized on one platform. The ad hoc development of many of the existing systems has led many to question the utility of the systems. The interviewees also pointed out that all of the data for these systems is generated at the local level and that any system is only as good as the data entered by those at the local level, whether it is the hospital, laboratory, or health department.

Table 7. Limitations of Current Systems

	Public Health	***Academia***	***Homeland Security***
Numerous systems and entities are collecting data, all are collecting various types of data, they all generate a different picture, and none are connected or integrated.	X	X	X
Systems were designed with no guidance and standards. Lacking a well-defined mission and no standards for definitions, user access, data ownership, or information sharing.	X	X	X
Syndromic Surveillance—questionable utility, especially at a national level. Will not be the first indication of an outbreak.	X		X
Current systems are balkanized. They have limited access, are limited by data gathered, including local reporting capacity, laboratory testing capacity, and response capacity	X	X	
No national system in place to advance the state of knowledge on surveillance and biosurveillance through funding, researching, and sharing best practices	X	X	
No common operating picture where all information can be visualized on one platform	X		
Still paper-based with communication up the chain and the distillation of pertinent information to make informed decisions	X		

	Public Health	*Academia*	*Homeland Security*
Usefullness decreases if others try to interpret the public health needs for biosurveillance	X		
Early event detection has been incorporated into biosurveillance systems in an ad hoc way resulting in questionable results.		X	
Outbreak detection is about the phone call. It is about relationships and a network. The systems support detection.	X		

C. BARRIERS

Many of the challenges faced by those conducting disease surveillance and biosurveillance activities stem from difficulties obtaining the needed information or from the lack of availability of the needed information. Barriers to information sharing were discussed at length during the interview process and the common themes are detailed in Table 8. System design and development was identified by all three professional groups as a barrier to information sharing. This issue was identified earlier in the Table 7 as well. Another systemic issue, identified during the interview process, is the weak public health surveillance infrastructure; poor ground-level surveillance and reporting; and limited laboratory capacity. This may be a direct result of another barrier cited by the interviewees, funding, and resource challenges. Because of funding and resource challenges, it is difficult to build and maintain the infrastructure for information sharing. Other barriers mentioned during the interviews included legal and institutional barriers, such as HIPAA, technological barriers, the resistance of states to requirements on disease surveillance and reporting being imposed by the federal government, and the "culture of information sharing" or the lack of willingness to share information. The willingness to share information is an important aspect to establishing situational awareness and common operating picture and is a continued challenge faced by many sectors.

Table 8. Barriers

	Public Health	Academia	Homeland Security
Separate and independent development and evolution of surveillance systems creates inability for systems to share information	X	X	X
Weak public health surveillance infrastructure - Poor ground-level surveillance and reporting and limited laboratory capacity for diagnostic testing	X		X
Funding and resource challenges make it difficult to build and maintain infrastructure	X		X
Health data privacy (HIPAA) and other legal and institutional restrictions are an impediment to information sharing and research		X	
Technological barriers	X		
States' resistance to the federal government imposing requirements on disease surveillance and reporting	X		
"Culture of Information Sharing"—lack of willingness to share information—including data, types of systems, contact			X

D. IMPROVING INFORMATION SHARING

Since information sharing is the basis for effective biosurveillance initiatives, it is imperative that there are few impediments to the process. There are many barriers, as noted above; however, the interviewees had many suggestions to improve information sharing (Table 9). One of the most promising initiatives is the move to electronic health records, health information exchanges, and meaningful use.[3] These three initiatives are

[3] "The American Recovery and Reinvestment Act of 2009 specifies three main components of Meaningful Use: 1) The use of a certified Electronic Health Record (EHR) in a meaningful manner, such as e-prescribing. 2) The use of certified EHR technology for electronic exchange of health information to improve quality of health care. 3) The use of certified EHR technology to submit clinical quality and other measures. Simply put, "meaningful use" means providers need to show they're using certified EHR technology in ways that can be measured significantly in quality and in quantity". "CMS HER Meaningful Use Overview" Centers for Medicare and Medicaid Services https://www.cms.gov/EHRIncentivePrograms/30_Meaningful_Use.asp.

the most promising steps toward the ability to have a truly integrated national biosurveillance system. These initiatives could establish a strong foundation for an integrated national biosurveillance system to build upon. This may also enable all of the parts of the surveillance system to work together, as noted by the interviewees, in a more efficient and effective way. Another important aspect that is mentioned in the literature and by the homeland security interviewee is the need for federal leadership. This is an extremely important aspect of the overall planning, design, and implementation of an integrated national biosurveillance system. The federal leadership can provide prioritization, an overarching organizational strategy and direction, as well as enforce the legislation pertinent to an integrated national biosurveillance system. The federal leaders must also address policy issues related to information sharing so that it does not continue to be seen as a barrier to information sharing between and among various agencies and jurisdictions. Given that most traditional disease surveillance data comes from the local level, which is then transmitted to the state and then federal level, the interviewees noted that the systems must be useful to states. Local and state agencies may be much more willing to allow information from their systems to be integrated into a larger national system if the overall system is useful for the local and state purposes as well.

Table 9. Ways to Improve Information Sharing

	Public Health	Academia	Homeland Security
New technologies—electronic health records, health information exchanges, meaningful use	X	X	X
All parts of the surveillance system needs to work together	X	X	
Generate stakeholder buy-in and partnership through involvement in development and planning.	X		
Prioritize activities by addressing one initiative at a time	X		
Create systems that are useful for states	X		
Training and capacity building to address poor surveillance and reporting	X		

	Public Health	Academia	Homeland Security
Need federal leadership to organize the strategy, provide direction, and enforce the existing legislative mandates			X
Lab Specimen Collection, Submission, and Testing Capacity	X		
Policy gets in the way			X

E. IMPROVING EXISTING SYSTEMS

Not only did the interviewees discuss ways to improve information sharing, a large amount of the discussion focused upon ways to improve the existing systems (Table 10). Existing disease surveillance and biosurveillance systems are the foundation for an integrated national biosurveillance system; therefore, it is vitally important that these systems function at the highest level possible. Much of the suggestions for improvement revolve around developing a solid foundation, building capacity, training, and collaboration. All three professional groups interviewed noted the importance of building a solid foundation for biosurveillance, situational awareness, and common operating picture through a well-defined mission, definitions, and standards. They also thought it was important to conduct basic research relative to the existing systems, including capabilities, best practices, and opportunities for development of new methods to gather data and information. Two of the three professional groups interviewed identified the need to build capacity at the local level for surveillance through funding, training/workforce development, staff retention, partnerships, and further development of system capacity. One of the most fundamental ways to build capacity outside of the actual system is through training and workforce development. The interviewees noted that reporting within and across agencies could be improved through education and training of end-users and legislators about disease surveillance, reporting, functionality of existing systems, the statistical processes that drive the data analysis, information sharing practices, and the HIPAA (Health Insurance Portability and Accountability Act of 1996) law. Other actions that the interviewees noted were the need for collaboration and

stakeholder buy-in. This, as discussed during the interviews, can be achieved by involving the stakeholders in the planning and development phases of systems or of an integrated national system, as well as generating a common understanding of the need for information sharing and the overall purpose of a national common operating picture and situational awareness.

Policy change was also mentioned during the interview process. Policy change is a challenging subject, but it is a necessary discussion in regard to creating an integrated national biosurveillance system. The homeland security professional noted the fact that there is a disconnection between the operations (the field) and policymakers. This makes policy change difficult because those who are making policy do not necessarily understand the operations of the systems. Additionally, the HIPAA law and other health information safeguards were mentioned as areas where policy change or other actions might improve information sharing. Federal government involvement with policy change, enforcing policies, and legislative mandates was noted as a needed action to improve the overall enterprise.

Table 10. Further Actions to Improve Systems

	Public Health	Academia	Homeland Security
Develop a solid foundation for biosurveillance, situational awareness, and common operating picture with a well defined mission, definitions and standards: define terms, case definitions, data needs, software needs, infrastructure etc.	*X*	*X*	*X*
Investments in basic research to identify capabilities of existing systems, best practices, develop basic biosurveillance capabilities, and identify opportunities for development of new methods to gather data and information.	*X*	*X*	*X*
Build capacity at the local level for surveillance through funding, training/workforce development, staff retention, partnerships, and further development of system capacity.	*X*		*X*

	Public Health	Academia	Homeland Security
Improve reporting within and across agencies through education and training about disease surveillance, reporting, functionality of existing systems, and statistical processes	*X*	*X*	
Build upon existing systems at the state and local level and platforms to integrate information, not specifically data—to progressively move those systems into a Common Operating Picture framework.	*X*	*X*	
Integration is difficult. Requires time and manpower to pull all the systems together and to ensure that an appropriate mix and separation exist.	*X*		*X*
Generate stakeholder buy-in of public and private agencies and organizations through involvement in development and planning, creating a willingness to participate and collaborate for data sharing and integration	*X*		*X*
Expand access to local systems and identify appropriate "levels of access to data"	*X*		*X*
Systems can be improved to better manage and visualize the data, including the ability to visualize the entire scope of a patient visit, including emergency department information, pharmacy data, outpatient visits, imaging orders and results,	*X*		*X*
Legislation must provide financial incentives to improve surveillance capacities and to share information	*X*		*X*
Address data and health information-sharing safeguards and obstacles that hinder the development of a national system, including incentivizing information sharing and cooperation among and between agencies.		*X*	*X*
Education and training for policy makers and end-users on system operations and needs; information-sharing practices, including HIPAA law, to spawn generational change.		*X*	*X*

	Public Health	Academia	Homeland Security
Develop a shared understanding of needed information for biosurveillance, the means through which that information can be shared, the overall purpose of a national system and the purpose of national situational awareness and common operating picture.	X		*X*
Review and identify lessons learned from literature and the experiences in other fields such as the Department of Defense (definition of situational awareness) and Private Industry (Statistical Process Control Methods).		*X*	
No comprehensive listing of existing systems in the U.S. A federal effort to create a federal interagency registry of systems that includes point of contact information, system goal, type of data collected, would allow for a network to be established to integrate systems.			X
Need federal leadership to organize the strategy, provide direction, maintain and/or increase funding, and enforce the existing legislative mandates			X
Establish or enforce laws that require reporting from physicians, long term care facilities, health departments and schools	X		
Policy change is difficult because of the disconnection between operations and the policy makers.			X

F. STANDARDS DEVELOPMENT

Standards were discussed at length by all interviewees. The common themes are described in Table 11. There is an immense need for the development of standards related to many aspects of information sharing, disease surveillance, and biosurveillance. According to the interviewees, standards are the basic foundation of the entire disease surveillance and biosurveillance enterprise. There is a need for standard definitions for situational awareness, "syndromes," biosurveillance, and "cases." The interviewees also

note the need for informatics standards, data and information exchange standards, coding standards, detection algorithms, and roles and responsibilities for users. Standards development is the cornerstone of the success of an integrated national biosurveillance system. There should be standards across disciplines and systems so that the information contained within disparate systems can be merged to create an overall common operating picture and situational awareness at all levels.

Table 11. Standard Development

	Public Health	Academia	Homeland Security
Informatics standards should be developed along with the tool	X		X
Data/information exchange standards	X		X
Coding standards, reporting standards, standard case definitions	X		X
Standard definitions for biosurveillance		X	X
Standard definitions for "syndromes" in syndromic surveillance		X	X
Standard detection algorithms		X	
Define situational awareness		X	X
Define standards for system access and control		X	X
Roles and responsibilities at different levels should be identified and defined			X

G. LEVELS OF ACCESS

In line with defining roles and responsibilities of those using the system, it is also important to set standards that define the levels of access for users, particularly in regard to an integrated national biosurveillance system. Table 12 shows the common themes related to levels of access. The overall consensus of the group is that access and permissions should be role based. The professional groups also identified issues with

system access, including privacy issues, too many people with access allows for information to be spread too widely, and the fact that the more access that is granted the more complicated the system becomes. This is a justification for role based permissions and limiting access to aggregate data for those who are outside of the agency that owns the data or do not have a need to know. Protecting the information contained within the various systems is paramount in creating a culture of trust between the agencies that are providing data.

Table 12. Should All Levels Have Access?

	Public Health	Academia	Homeland Security
Access and permissions should be role based	X	X	X
Yes, aggregate information. Not to specific patient information	X		
Granting access to all levels is good for situational awareness but can cause issues if information is spread too widely.	X		
Access to all levels would be nice but not sure it is feasible, may be privacy issues.		X	
The more access you allow the more complicated the system becomes and it becomes more difficult to manage the users within the system		X	

H. INTEGRATION OF CURRENT SYSTEMS

As noted previously, there are numerous systems that exist at all levels—private sector, local, state, and federal. This section discusses the total integration of all of these existing systems and their information to improve information sharing across jurisdictions for rapid detection, situational awareness, and common operating (Table 13). This integration would essentially create a "system of systems" to establish an integrated national biosurveillance system. All of the professionals interviewed had differing viewpoints as to whether the systems could be integrated and what is needed to

accomplish the integration. Some of the interviewees identified reasons as to why the integration would not be possible or why integration would not be useful. Overall, for systems to be integrated there must be a leader, a well-defined mission, stakeholder involvement, and they must meet the needs of all levels of players from the national to the local level. One "system in the sky" will not work; however, data needs to be gathered electronically and the ability to analyze the data at all levels is important so that various operating pictures can be developed based upon need.

Table 13. How Could Existing Systems be Integrated?

	Public Health	Academia	Homeland Security
Missions must be well-defined	X		
CDC should take a leadership role	X		
Get stakeholders involved	X		
Need a comprehensive operating picture across the board, not just certain programs within CDC working independently.	X		
Would work at the national level but players at all levels have access and it is useful to meet their needs and can meet national needs.		X	
Having a "system of systems" that would collect information from various existing systems to establish a national picture makes sense		X	
A "system in the sky" that does everything will not work		X	
Information should be gathered electronically (automated push and pull from all levels), cannot rely upon the provider to enter and move data.			X
Must be a way to get the broader picture and scale it down to the level needed			X

	Public Health	Academia	Homeland Security
Make tools available to analyze local data and interact around local data.			X

I. INTEGRATION OF NATIONAL SYSTEMS AND ONE PRIMARY COLLECTOR

There are numerous national systems that gather data and information from local and state agencies, as well as the private sector. This section discusses the integration of the existing national systems and the information contained within those to create an integrated national biosurveillance system. This integration would in essence create a "system of systems" from all existing national systems. The interviewees were asked their opinion as to whether the existing national systems could be integrated to form national biosurveillance system (Table 14). The consensus of the professionals interviewed was that it would be great if an integrated national biosurveillance system could be created; however, most national systems were not designed for integration; therefore, an integrated national system did not seem possible. Conversely, one public health professional did note that there is a possibility for some national systems, such as NNDSS, PulseNet, and FoodNet, could be integrated because they are already linked in some fashion through the current reportable disease systems. In this discussion, one professional identified the need for federal leadership for the national biosurveillance project.

Table 14. Could the National Systems Be Integrated to Form a National Biosurveillance System?

	Public Health	Academia	Homeland Security
Most existing national systems are not useful, not designed for integration and what value would a national system be to states?	X	X	

	Public Health	Academia	Homeland Security
Very far away from an integrated system—not sure an integrated national system is possible		X	X
A national picture is not going to help with state situational awareness because states already have their own data to create situational awareness.	X		
In a sense, existing state surveillance systems' data are integrated with the National Notifiable Diseases Surveillance System (NNDSS); it's just not near real-time.	X		
Definitely think so—systems such as NNDSS, PulseNet, FoodNet, are already linked in some fashion through the reportable disease system and have the ability to identify national-level outbreaks and unusual cases.	X		
Would be great if a national system could be created		X	
A "system of systems" sounds good but individual systems have difficulty operating, this compounds with a "system of systems".			X
No leader to lead the effort for biosurveillance integration.			X

As with the responses to whether the existing national systems could be integrated, the interviewees had mixed opinions as to whether one existing national system could serve as a primary collector. Table 15 shows the responses from each professional group. No one could identify a single national system, with the exception of the homeland security professional, that might serve as the primary collector of biosurveillance data. This interviewee stated that the National Biosurveillance Integration Center was supposed to be the integrated national biosurveillance system. They went on to state that this center is not working well as a "system of systems" because it has difficulty obtaining needed data. This was an issue also identified throughout much of the literature. Overall, the interviewees could not conceptualize an

all-encompassing system or a one-stop shop. However, they did offer ways to possibly achieve integration, including maintaining individual system integrity, building capacity, and a map and master plan that details the end result.

Table 15. Is There One System that Could Be Used as the Primary Collector?

	Public Health	Academia	Homeland Security
As the primary collector from all sources? No, an all-encompassing system seems too overwhelming.	X		
Cannot conceptualize having a one-stop shop.	X		
It is possible will take building over time.	X		
Maintain individual system integrity but feed the overall system.	X		
Complicated but doable.	X		
Build capacity in small ways to get to the bigger picture.	X		
To have an integrated national biosurveillance system you need a map and a master plan that details the end result.	X		
Difficult to develop because of changes in leadership and priorities.	X		
Not familiar with one—BioSense or ESSENCE might serve as the basic foundation for a national system.		X	
So far away from that. People have tried to use one system and it did not work.			X
National Biosurveillance Integration Center (NBIC) is supposed to be an integrated national biosurveillance system—does not work well as a "system of systems"			X

J. BENEFITS OF AN INTEGRATED NATIONAL BIOSURVEILLANCE SYSTEM

Even though the professionals who were interviewed could not identify one system, nor were they sure that one system could be the primary collector of information from the various systems nationwide, they did see some benefit to an integrated national biosurveillance system. The primary benefit stated by two of the three professional groups is the fact that presently no national picture exists. An integrated national biosurveillance system would be beneficial for creating a common operating picture and situational awareness; however, they stated it could not be used as an early event detection and warning system. As noted in Table 16, the phone call at the local level is still the best early warning and notification system and nothing will replace that. The interviewees also stated reasons that an integrated national system would not be beneficial. The public health professionals indicated that a national system would only be beneficial if managed and owned by public health because other sectors had differing priorities and requirements. The public health professionals also stated that there is not always a need for integrated data. Some systems are designed to be separate and have specific missions. Although the public health professionals did not see a need for all data to be integrated, they did state that national systems and initiatives have a place. However, as stated in regard to other questions, there must be national priorities and planning accompanying the national initiatives.

Table 16. Benefits of an Integrated National Biosurveillance System

	Public Health	Academia	Homeland Security
Currently no national picture exists, would be beneficial for creating common operating picture and situational awareness but not for early event detection and warning.	X	X	
National systems and initiatives have a place but there should be national priorities and planning	X		

	Public Health	Academia	Homeland Security
A national system is only beneficial if managed and owned by public health because of differing priorities and requirements	X		
Depends upon the interpretation of integration. Not always a need for integrated data, some systems are designed to be separate. Systems have separate missions—reportable diseases, syndromic surveillance, immunization registries, etc.	X		

K. ROADMAP FOR IMPLEMENTATION

A roadmap for implementation is one method for establishing national priorities and planning for an integrated national biosurveillance system. The interviewees were asked if they were familiar with a roadmap for implementation of an integrated national biosurveillance system. Their responses are shown in Table 17. The professionals had various answers, all of which pertained to federal legislation or initiatives. Two professionals stated that there probably was but that they were not aware of any. These statements reinforce the earlier statements regarding the need for federal leadership and a roadmap or national priorities and planning.

Table 17. Roadmap for Implementation of an Integrated National Biosurveillance System

	Public Health	Academia	Homeland Security
The Pandemic and All-Hazards Preparedness Act (PAHPA) was the initial roadmap or plan.	X		
The National Response Framework (NRF) from an overall preparedness standpoint.	X		
National Biosurveillance Strategy	X		
NEDSS-based reporting requirements	X		

	Public Health	Academia	Homeland Security
Probably is but I am not aware of any.	X	X	
Department of Homeland Security is working on a strategy for the National Biosurveillance Integration Center (NBIC)			X

L. CONCEPTUAL MODEL

The creation of a conceptual model for an integrated national biosurveillance system is one way to meet the need for a roadmap and national priorities and planning (Table 18). Many of the professionals interviewed felt that a conceptual model would be useful in giving a roadmap for implementation, including establishing governance, roles and responsibilities, and accountability. It allows for stakeholder involvement in the planning process through dialogue. Challenges to the development of a conceptual model were also identified. These included the sheer challenge of developing a model, the past issues with developing organizational models, and the fact that many agencies are reluctant to work within a network. The homeland security professional also offered two ways to look at a conceptual model, as one that shows all the information flowing up before it flows over or as a true network that allows for multiple actions simultaneously. Overall, the responses were positive that a conceptual model for an integrated national biosurveillance system would be useful in the overall development of the system.

Table 18. Usefulness of a Conceptual Model for Integrated National Biosurveillance System

	Public Health	Academia	Homeland Security
It is critical—must establish governance and roles and responsibilities, and accountability	*X*		
Use a community planning model to generate stakeholder involvement and outline roles and responsibilities	*X*		

	Public Health	Academia	Homeland Security
Stakeholder involvement in the planning process is important for building capacity	*X*		
Helps identify leadership, to organize initiatives, and how the initiatives are defined and implemented	*X*		
Yes on a number of levels 1) research benefits in describing the model; 2) allows assessment of system and process; 3) allows dialogue to occur between stakeholders		*X*	
Gives a roadmap for implementation		*X*	
Allows for planning to accomplish goals		*X*	
Gives an overall process for the system.		*X*	
People have been trying to come up with a model for quite some time. Has encountered problems.			*X*
Some have suggested that the system exist outside of any federal agency to avoid "ownership" issues.			*X*
Issue is most agencies want to be autonomous.			*X*
Having a diagram sounds good but getting there is challenging.			*X*
Two ways to look at the diagram: 1) it is a diagram of everything flowing "up" in an agency and then over; or 2) it is a network that allows multiple actions at the same time.			*X*
Agencies tend to be very hierarchical and cannot share information until the Secretary knows about it.			*X*
At network is much stronger but people are reluctant to work in that environment.			*X*

There are various systems today that cover a range of missions, which include: traditional disease surveillance, early detection, situational awareness, notification, communication, integration of response and information sharing, and laboratory surveillance. They are all beneficial in their own right; however, there are ways in which

the systems and the overall practice of information sharing could be improved. The interview process generated numerous recommendations for improvement for existing systems, including standard development and policy change. The lack of standards and the challenges associated with existing policies were discussed as barriers to the overall process of information sharing, specifically where health data privacy is concerned. The overall consensus of those who were interviewed is that an integrated national biosurveillance system might be beneficial, if the federal government will take the lead in planning and development, along with stakeholders, to set forth an overall roadmap for integration.

V. FINDINGS

There is a substantial amount of discussion and some effort within the public health and medical enterprise in the United States and worldwide regarding ways to improve information sharing across jurisdictions and sectors to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture. Information sharing, specifically related to the public health and medical enterprise, is imperative for rapid detection and response to outbreaks and is the cornerstone of the establishment of situational awareness and common operating picture. Therefore, creating a mechanism to achieve that end is necessary, as identified in much of the literature related to homeland security and health security.

The findings in this study reinforced many of the gaps discovered in the review of the literature. Specifically, that there is no overarching roadmap for improving information sharing, there is no process for creating an integrated national biosurveillance system, the existing organizational structure does not facilitate collaboration between existing entities nor the integration of existing systems, and no entity has been identified to lead the activities related to creating an integrated national biosurveillance system. These findings along with others from both the case studies and the interviews will be expanded upon in this chapter.

Categories were created during the analysis of the case studies and interviews, which relate back to the research questions. This chapter will be structured around the research questions and the findings will be discussed using the categories developed in the analysis chapters. This research had one primary research question with three sub-questions. The sub-questions are answered first, with the primary research question being discussed last in the chapter, as this provides a summation of the findings from the sub-questions.

A. CURRENT SYSTEMS AND THEIR USE

What systems are currently used to provide situational awareness and a common operating picture, during naturally occurring or intentional disease outbreaks, or exposures and what are the current limitations of these systems?

The primary use of most of the systems that exist today is detection, mitigation, and prevention of disease or illness. Other uses of the systems that are noted in the case studies and interviews are analysis, visualization, reporting, early detection, traditional disease surveillance, case tracking and follow-up, notification, and communication. Most of the systems studied provide situational awareness; very few are identified to provide a common operating picture. The use of the incident command system was noted in the interviews as being successful in improving information sharing for common operating picture and situational awareness between agencies through integrating the public health and medical enterprise response with traditional first response agencies. The interviews and case studies demonstrated that there are numerous systems that exist at the local, state, and national level, many of which function independently and have a single mission. Most of these systems are limited to functioning in a traditional disease surveillance role, and a few provide some form of biosurveillance.

B. LIMITATIONS

The fact that there are so many systems that collect a wide variety of data is a limitation that was identified during the interviews. In the public health and medical enterprise, there are systems that exist in the private sector, at local health departments, regional health departments, state health departments, the federal level, and other private sector entities. These systems collect and process a wide range of data from various sources, including syndromic surveillance data, over-the-counter pharmacy sales, immunization records, communicable disease reports, laboratory test results, patient encounters, insurance data, etc. Many of the existing systems are balkanized, compartmentalizing the data collected and generally not sharing outside of the systems. This compartmentalization of systems greatly impedes the information-sharing process.

Presently, many public health reportable disease systems are still somewhat paper-based systems, with data collection primarily relying upon faxed reports from physicians' offices and laboratories.

It is also noted throughout the literature, case studies, and interviews that the local level is the primary collector of data and because of that, the systems are limited to the quality and quantity of data collected and entered at the local level. There was little forethought put into the development and design of many of the existing systems in terms of standardized data structures and interoperable application level programming; therefore, the system infrastructure limits the overall ability of those systems to share information to create a common operating picture and situational awareness. A general lack of data collection and information-sharing infrastructure and methods to conduct a response was also identified as a limitation. This stems partly from a lack of collaboration in the planning, development, and use of the existing data collection and information-sharing systems. The lack of collaboration is a significant barrier, noted in many different areas of the case studies and interviews, including as being a limitation to the existing systems as well as a barrier to information sharing.

C. BARRIERS TO INFORMATION SHARING

What are the barriers to information sharing in the current public health/medical enterprise?

There are numerous barriers that were identified in the literature, case studies, and interviews. The broad categories that emerged were the issues related to privacy of personally identifiable health information; the information-sharing culture; scientific and technical barriers; data collection issues; and organizational and financial barriers.

1. Information Privacy/Information-Sharing Culture

The analysis of the interviews illustrated that there is a general reluctance in the public health and medical enterprise to share data and information between and among jurisdictions because of the fear of a health data privacy violation. Stemming, in part, from fears of health data privacy violations, a "culture" of information sharing has

developed, meaning the lack of willingness to share information between and among entities and jurisdictions. In addition to the fears, the interviews noted a general lack of understanding or knowledge within the health and medical enterprise related to health data privacy legislation, such as the HIPAA law.

2. Scientific and Technical Barriers

Scientific and technical hurdles are identified as a primary barrier to information sharing, including system design, lack of knowledge of existing systems, and resistance to new systems or to new system integration efforts. The interviews and case studies noted that there are few people who know how to adequately use the existing systems or those who use the systems are not adequately trained to use them. Lastly, there is a general resistance to the development of new systems or to efforts to integrate the existing systems. The interviews noted that the resistance to new systems and to integration efforts may originate from the states' desire to retain their Tenth Amendment power for public health law, including their desire to not have disease surveillance and reporting requirements imposed upon them by the federal government.

3. Data Collection

Data collection was identified as a barrier to information sharing for a number of reasons, including the fact that it is laborious and time-consuming, and often generates false-positive alerts. Specifically in regard to systems that are still predominantly paper-based, data collection requires phone calls and faxes to and from various entities within the public health and medical enterprise. Once this data is received, it must then be manually entered into an electronic system before it can be shared efficiently with other entities. Additionally, the overall public health surveillance infrastructure is weak, primarily because of poor ground-level surveillance, limited epidemiological capacity, and limited laboratory capacity.

4. Organizational/Financial Obstacles

Organizational obstacles and financial obstacles are also noted as significant barrier to information sharing. The interviewees stated that organizations may be

reluctant to share the data that they collect. There are many reasons for this, including the fear of identifying deficiencies or weaknesses within private sector facilities or for fear of releasing proprietary information. Moreover, organizations may have internal restrictions related to information sharing, to protect from health data privacy violations.

In the past few years, funding for the development and maintenance of disease surveillance and biosurveillance systems has been decreasing, as noted during the interviews. Due to the funding decreases, these systems may not have been upgraded to meet interoperability standards or there may not be enough funding to maintain appropriately trained staff to use the system.

D. IMPROVING EXISTING SYSTEMS

How can the current systems be used, and what further actions can be taken to more rapidly detect and respond to outbreaks and to create better situational awareness and a common operating picture?

Existing disease surveillance and biosurveillance systems are the foundation for an integrated national biosurveillance system and improvements to those systems are needed so that they function at the highest level. As such, the overall analysis revealed that developing a solid foundation for disease surveillance and biosurveillance systems, through leadership, standardization, and building local capacity, is crucial to improving information sharing. This includes the identification or creation of definitions, standards, a well-defined mission, well-defined data needs, software requirements, and infrastructure. Having a solid foundation for disease surveillance and biosurveillance systems provides a mechanism for the production and sharing of high-quality data and information, thereby adding value to the existing systems and potentially reducing the stakeholders' reluctance to share information and to the potential integration of systems. Additionally, building local capacity for disease surveillance and biosurveillance via training and stakeholder collaboration is key in optimizing such systems and emerged as themes during the interviews. These themes compliment those discovered when

analyzing the case studies that included mechanisms to achieve these improvements—evaluation and testing, protocols, daily use, stakeholder coordination and partnerships, resource availability, and a competent workforce.

1. Leadership

Federal leadership was identified as a mechanism to improve existing systems. This leadership, as noted in the interviews, includes strategy development that provides organization and direction; stakeholder education; policy development, policy change, and enforcement.

a. Strategy

The interviewees noted that there are some strategies that exist in regard to information sharing for improving situational awareness and common operating picture, such as the PAHPA and the National Biosurveillance Strategy. However, two of the professionals stated, in regard to strategies to improve information sharing, that there "probably was but they were not aware of any." The strategies that were mentioned were federal-level initiatives that had not had overwhelming success in setting a path for achieving information sharing across jurisdictions and sectors to achieve situational awareness and common operating picture. An overall strategy for information sharing, as discussed in the interviews, is a mechanism that could provide clear guidance, organization, and direction for stakeholders.

b. Stakeholder Education

The analysis of the interviews demonstrated the fact that policy change and enforcement requires stakeholder and legislator buy-in. Therefore, it is important that stakeholders and legislators are educated about disease surveillance, reporting, functionality of existing systems, the standard processes driving the data analysis, information-sharing practices, and the HIPAA law. The interviewees stated that education of policy makers and legislators can establish a foundation of understanding within those groups so that they may affect policy change and ensure that polices are effectively enforced.

c. Policy

Existing policies, such as the HIPAA law and other health information safeguards were identified as areas where policy change may improve information sharing and the disease surveillance and biosurveillance systems overall. In addition to policy change, existing policies that require information sharing and the fact that they are not enforced was discussed. The interviewees noted that the federal government should take a leadership role and enforce the information-sharing polices that exist and lead efforts to change those that are not effective. Although existing policies and policy change was identified as a major barrier to information sharing, the overarching theme that emerged from the case studies and interviews is systemic issues must be addressed. Systemic issues related to information sharing may be addressed through standardization.

2. Standardization

Standardization was identified as an issue in both the case studies and interviews. Standardization would allow disparate systems to be more easily integrated and facilitate the establishment of a strong foundation of local reporting systems. Standardization, involves numerous separate activities. It may be achieved through evaluation and testing, standard protocols, standard software requirements, standard infrastructure requirements, definitions, a well-defined mission and goals, and levels of access.

a. Evaluation and Testing

Evaluation and testing were identified as mechanisms to improve existing systems, to enhance information-sharing capabilities, and to create situational awareness and a common operating picture. Evaluation and testing were discussed in the interviews as a way to identify capabilities of existing systems, identify best practices, develop basic biosurveillance capabilities, as well as identify opportunities for the development of new methods to gather data and information. The case studies also noted that evaluation and testing would assist in the development of new technologies, but more importantly, the development of standards for information sharing.

b. Standards Development

Standards were a relatively significant thread throughout most of the responses during the interview process as well as the case studies. The development of standards is the cornerstone to improving existing systems, information sharing, and in the movement toward an integrated national biosurveillance system. The case studies and interviews identified standards that needed to be improved or developed, including standardized content and definitions for disease-syndrome classification and reporting; basic informatics standards; data and information exchange standards; and standards for access and control.

c. Standardized Content and Definitions

Standardized content and definitions are a small part of the overall effort to improve existing systems and information sharing; however, they are the underpinning of information sharing for the entire public health and medical enterprise. Regarding standardized content and definitions, the case studies and interviews noted that there presently were various standards in the public health and medical enterprise related to information sharing. The interviews were more specific in identifying standardization needs. This included coding, reporting, and standard case definitions; defining biosurveillance and situational awareness; syndrome definitions; and standard detection algorithms. Standard content and definitions can facilitate information sharing between and among jurisdictions and sectors. Increased information sharing between various entities enhances the need for standard levels of access.

d. Levels of Access

Standardization includes the identification of roles and responsibilities of the various participating agencies and stakeholders, as well as levels of access to information shared between and among sectors and jurisdictions. The interviewees stated that access to an integrated national biosurveillance system should be role based, and limit access based upon “need to know” and “need to share.” It was specifically noted in the interviews that access levels would add a dimension of complication to the system. Nonetheless, the interviewees stated that levels of access are needed, so that information

is shared at appropriate levels, all stakeholders are invested in the process, a culture of trust is created between all agencies involved, and the overall reluctance to share information and participate in integration efforts is reduced.

3. Building Local Capacity

It has been stated numerous times throughout this research that disease surveillance and biosurveillance begins at the local level. Hence, it is important for the local level to have the capacity to perform at a high level and collect quality data. Building local capacity is a large endeavor because it entails many things. The case studies and interviews mentioned the following ways to build local capacity including, building and retaining a competent workforce, assuring funding and resource availability, developing and maintaining infrastructure, and collaboration and coordination with stakeholders.

a. Competent Workforce

Trained professionals are the basis for reliable and valid disease surveillance and biosurveillance. Therefore, based upon the analysis of the case studies and interviews, it is vitally important that those who are using the systems are trained and competent in system operation and data analysis, as well as disease surveillance and reporting. Trained professionals increase the reliability and validity of the outputs of existing systems, thereby increasing the overall reliability and validity of an integrated system. Once professionals are trained, daily use of the various information-sharing systems builds skills and maintains a competent workforce. It is also important, as noted in the interviews, to retain a competent workforce so that local systems continually produce valid and reliable data. Trained professionals are a commodity and funding to retain that workforce is important.

b. Funding and Resources

Funding for disease surveillance and biosurveillance capacity at the local level has started to decrease in recent years, as noted in the interviews. Local capacity cannot be developed or maintained without appropriate funding and resources. Often, as

noted in the interviews, financial incentives are the only way to improve surveillance capacities and prompt organizations to share information. Funding and resources provide the opportunity for the local level to build capacity through workforce development and retention along with the development of solid infrastructure for information sharing.

c. Infrastructure

Existing systems are built upon many different platforms and operate independently of one another. The infrastructure, as discussed in the interviews and case studies, they use does not facilitate information sharing between and among jurisdictions and sectors. The existing infrastructure is the foundation of local disease surveillance and biosurveillance systems. Improving the existing infrastructure, as noted in the interviews, could build local capacity, improve individual systems, facilitate information sharing, and encourage collaboration and coordination of various stakeholders.

d. Collaboration and Coordination

Improving existing systems and building local capacity requires a collaborative effort, as discussed in the case studies. Stakeholder buy-in is important to the overall success of information-sharing initiatives. It also allows for the development of a shared understanding of the information needs, what information can be shared, mechanisms that can be used to facilitate information sharing, and an overall understanding of the purpose of information sharing. This may lead to a reduction in the reluctance of organizations to participate in integrated systems.

E. INTEGRATION OF CURRENT SYSTEMS

One of the approaches suggested in the literature to improve information sharing for common operating picture and near real-time situational awareness is the integration of existing systems, including national systems. The interviewees were asked if these systems could be integrated or if it was impossible. The interviewees had differing viewpoints related to this question, including why the integration would not be possible or why it would not be useful. The interviews revealed that the challenge of integration lies in the fact that there are so many systems that exist across the spectrum from the

private sector to the national level. A few national systems were noted in the interviews, which could possibly be integrated to form a piece of a national biosurveillance system. The themes that emerged in the analysis were there should be standards, a federal leader, and stakeholder buy-in, as well as the system must meet the needs of all levels of players from local to national. This, as identified during the interviews, should be one of the major functions of an integrated national system—the ability to have scalable common operating picture and situational awareness based upon jurisdictional needs.

F. INTEGRATION OF NATIONAL SYSTEMS AND ONE PRIMARY COLLECTOR

Although there are a vast number of current systems, there was no single system that the interviewees identified that could be used as the primary collector of information. It is important to note, as mentioned in one interview, that legislation established the National Biosurveillance Integration Center (NBIC) in the Department of Homeland Security for this specific purpose. Nonetheless, as also noted by the interviewee and in the literature, at present the NBIC is not functioning as was hoped because it is having difficulty obtaining the data needed to fulfill its mission. The reasoning behind the difficulties may be highlighted by the interviewees' responses, including the difficulty conceptualizing an all encompassing, one-stop-shop system, as well as other barriers to information sharing mentioned earlier in this chapter. Although the interviewees noted that an integrated national biosurveillance system was difficult to conceptualize, ways to achieve integration and facilitate successful information sharing were offered. This included maintaining individual system integrity, building capacity, federal leadership, a map, and master plan that detailed the end results of such a system.

G. BENEFITS OF AN INTEGRATED NATIONAL BIOSURVEILLANCE SYSTEM

Even though it is difficult to identify a single system to serve as the primary collector of biosurveillance data, the case studies and interviews identified the benefits of an integrated national biosurveillance system. The primary benefit is the establishment of a national common operating picture and situational awareness, as well as the ability to

generate state, regional, and local common operating picture and situational awareness. In regard to health security in the United States, the analysis indicated that having a common operating picture and near real-time situational awareness is vitally important. There are issues associated with having an integrated national biosurveillance system, including the differences in priorities and requirements, not always a need for integrated information, and the specific and separate missions of existing systems. Overall, the analysis indicated that a national system has tangible benefits and has a function to serve at all levels.

The main question, this thesis sought to answer is: *How can the public health/medical enterprise improve information sharing across jurisdictions and sectors, to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures, and to create better situational awareness and a common operating picture?*

The case studies and interviews identified strategies to improve overall information sharing, including the need for federal leadership and a roadmap for implementation of an integrated national biosurveillance system, which includes a conceptual model.

H. IMPROVING INFORMATION SHARING

Information sharing is the foundation for effective biosurveillance; therefore, it is vital that there are few impediments to the process. Although there were a significant amount of barriers to information sharing that were identified in the analysis of the case studies and interviews, the analysis also identified ways to address and overcome those barriers. The most promising initiative discussed in the interviews is the move to electronic health records, health information exchanges, and meaningful use. In addition, the interviewees stressed that policies must be addressed so that barriers to information sharing can be removed. Policy, as noted in the interviews, is one of the major impediments to information sharing, because often times the policies are misinterpreted and misunderstood. Improving information sharing is a small piece of the

overall improvements to existing surveillance and biosurveillance systems that was identified in the case studies and interviews that would create better situational awareness and common operating picture.

I. ROADMAP FOR IMPLEMENTATION

Presently, as stated in the interviews, there is no roadmap or implementation plan for improving information sharing or the creation of an integrated national biosurveillance system. Several initiatives were discussed during the interviews, including legislation, strategies, and initiatives, such as the Pandemic and All-Hazards Preparedness Act (PAHPA), the National Response Framework (NRF), the National Biosurveillance Strategy, and others. The fact that a definite strategy could not be identified reinforces statements made by the interviewees that there is a need for federal leadership and a roadmap outlining national priorities and planning.

J. CONCEPTUAL MODEL

One piece of an overall roadmap is the creation of an organizational model that outlines the ways in which information sharing can be improved to create better situational awareness and common operating picture. This, as discussed in the interviews, would be useful in providing a guide for capacity building, implementation, establishing standards, governance, roles and responsibilities, and providing accountability. The interviewees noted that the development of such a model is challenging. The major impediment to information sharing identified in the interviews and case studies was the reluctance of many agencies to work within a collaborative network. The overall consensus was that an organizational model for information sharing and an integrated national biosurveillance system would be useful in driving the initiative forward with a specific focus.

K. CONCLUSION

Based upon the review of existing literature and the analysis of the case studies and interviews, it is evident that information sharing can be improved to create near real-

time situational awareness and common operating picture. The interviewees stated that the road to improving information sharing is quite long and difficult.

The case studies and interview analysis identifies requirements for the public health and medical enterprise to achieve improved information sharing to create situational awareness and common operating picture, including three overarching themes, leadership, policy, and strategy. The analysis offers numerous means, some of which currently exist or are in development, to achieve these requirements and facilitate the process, such as standard development, policy change or development, capacity building, education, funding, stakeholder involvement, and, ultimately, federal leadership, with a roadmap for information sharing and for implementation of an integrated national biosurveillance system.

VI. LEAPS MODEL

A solid foundation in health information sharing and disease surveillance is paramount for the public health and medical enterprise to improve information sharing across jurisdictions and sectors to more rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture. There are three components that have emerged through the research as central to establishing this solid foundation to improve information sharing—leadership and national level policy and strategy related to standardization, capacity building, and collaboration and coordination.

This chapter will outline a conceptual model for the public health and medical enterprise to improve information sharing, based upon review and analysis of existing literature, the analysis of case studies, and interviews. This chapter will also attempt to establish a conceptual framework that is designed to improve information sharing through identifying leadership for the initiative; and by identifying and enforcing policies that will facilitate information sharing and the integration of the systems. Additionally, it will outline a strategy for standardization, to build capacity, and encourage collaboration and coordination at the all levels to facilitate information sharing across jurisdictions and sectors.

A. LEADERSHIP

The foundation of the LEAPS model (see Figure 1) is leadership; specifically the need for a leader to guide the overall information-sharing strategy development and to serve as the focal point with authority and resources to drive the effort forward. Leadership from one central entity is necessary to guide the initiative to improve information sharing through a collaborative effort, including policy development and enforcement, and the identification of a strategy to establish a strong foundation for information sharing and ultimately an integrated national biosurveillance enterprise.

1. Collaborative Leadership

A collaborative leadership effort is necessary to drive the efforts to improve information sharing in the public health and medical enterprise. Collaborative leadership is defined by the author of this thesis as that which fosters collaboration to solve agreed upon issues at each level of information processes. These levels include: private sector, local, state, and federal agencies. However, the overarching governance should come from the federal level. A single entity at the federal level should be identified to lead and coordinate the initiative, through collaboration with other federal stakeholders. This entity should be recognized by the White House as the leader of the initiative. All stakeholders should be mandated to collaborate with this leader to develop and implement all aspects of the initiative to improve information sharing. The leadership should be charged with the identification or development and enforcement of policies related to information sharing and an overarching strategy for information sharing and biosurveillance among federal, state, local, and private sector stakeholders.

B. IDENTIFYING AND ENFORCING POLICY

The second component of the LEAPS model is policy. Presently, there is a general lack of understanding and enforcement of many of the existing policies related to health data information sharing and ways to improve information sharing across jurisdictions and sectors. First and foremost, it is important that stakeholders understand existing policies; therefore, they should be educated on the nuances of the policies in existence to increase their understanding of the purpose, limitations, and allowances in order to facilitate information sharing across jurisdictions and sectors. The policies and the activities related to increasing the understanding of the existing policies should be addressed at the federal level to ensure continuity of the message and to ensure they serve their function to protect data but, at the same time, facilitate information sharing. Policies related to information sharing are not often strictly enforced at the federal level. Therefore, an effort, initiated at the federal level, should be made to enforce these policies so that information sharing is not impeded. In addition to increasing

stakeholders' understanding of policies and policy enforcement, new policies may have to be developed to encourage information sharing, specifically in regard to identifying or establishing a strategy for information sharing.

C. INFORMATION-SHARING STRATEGY

In order to achieve a coordinated effort to improve information sharing for the public health and medical enterprise, a single information-sharing strategy must be identified and communicated with stakeholders at all levels. This strategy should provide clear guidance, organization, and direction for stakeholders—providing an overarching national level framework for improving information sharing to create better situational awareness and common operating picture. This third component of the LEAPS model should include standards, a capacity-building element, and a mechanism to ensure collaboration and coordination between stakeholders at all levels.

1. Standards

Standardization is the mechanism by which the LEAPS model will establish the framework for a solid foundation for information sharing. Federal leadership should initiate an effort to standardize the information-sharing process. The development and identification of standards allows for interoperability between existing systems and new systems yet to be developed, which facilitates the information sharing across jurisdictions and sectors. Standardization efforts should include the evaluation and testing of existing and new technologies; development of standard protocols and requirements; standard definitions; and levels of access.

a. Evaluation and Testing

In order to achieve the goal of improved information sharing, the current state of existing information-sharing systems must be established. Evaluation and testing are mechanisms that can be used to assess the current status of the existing systems and to ensure that the public health and medical enterprise meets an established baseline for information sharing. A national tool for evaluation of disease surveillance and biosurveillance systems should be developed. All existing systems should be evaluated

with this standard tool to identify best practices, identify a baseline of surveillance and biosurveillance capabilities, and to make recommendations for improvements and identify opportunities for development of new technologies. Newly developed technologies should be evaluated and tested with this same standardized process. The evaluation and testing of existing and newly developed systems will allow for the identification and implementation of standards related to the information-sharing process.

b. Standards Development

Standards for information sharing are the cornerstone for improving existing systems, information sharing, and in the movement toward an integrated national biosurveillance system. Standards that can facilitate information sharing are: standard detection algorithms, data standards, interoperability standards, standardized content and definitions, and system access and control standards.

Standard detection algorithms for syndromic surveillance would standardize the methodology used for aberration detection within syndromic surveillance systems. Data and information exchange standards would establish a minimum set of requirements for the data points to be collected and transmitted from each level within the public health and medical enterprise, ensuring that each entity was consistently collecting the same information using the same methods. In addition to data and information exchange standards, having a baseline standard for interoperability for all systems facilitates information sharing across jurisdictions and sectors because all systems will have the necessary components to communicate with one another. Each of the activities listed thus far involve standardization of elements of the information-sharing systems. Standardized content and definitions are the underpinnings of data collection activities and levels of access prescribe the mechanism by which different entities have access to the data collected.

c. Standardized Content and Definitions

Standardized content and definitions establish the basis of public health and medical information sharing. This includes standard definitions for syndromes in syndromic surveillance, cases for public health disease reporting, and mechanisms for

coding disease information within information-sharing systems. These definitions must be established at or accepted by the federal level leadership and communicated to all stakeholders in the public health and medical enterprise. Above and beyond definitions for syndromes and diseases, there should be standard definitions identified by the federal leadership for situational awareness and common operating picture in the context of public health and medical information sharing, as well as a standard definition for biosurveillance. Having standard definitions for these central concepts for information sharing establishes a baseline for understanding and sets baseline criteria for all stakeholders in the public health and medical enterprise, which will facilitate information sharing.

d. Levels of Access

Identification of appropriate levels of access to the data and information being shared is an important aspect of the LEAPS model. Standardized levels of access provide a degree of protection for the data as well as facilitating information sharing. It fosters trust in the information-sharing system by ensuring that only those who "need to know" have access to the full data set and that others can gain situational awareness and common operating picture by having access to aggregate data. Standardized levels of access should be based upon two principles "need to know" and "need to share" and should be role and jurisdiction based. Access should be tiered, granting full viewing rights to those at appropriate levels who "need to know" and an aggregate set of viewing rights to those who the information is being shared with. Levels of access provide safeguards for those sharing and those receiving the information so that data privacy laws are not violated and help to reduce the general reluctance to share information among jurisdictions.

2. Building Capacity

Having the capacity to share information across jurisdictions is an important factor in improving information sharing to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture. Disease surveillance and biosurveillance

begin at the local level; therefore, it is vitally important that these entities have the capacity to perform these functions at a high level and collect quality data. Ways the LEAPS model offers to build capacity for information sharing are: building and maintaining a competent workforce, assuring funding and resource availability, developing and maintaining infrastructure, and collaboration and coordination with stakeholders.

a. Competent Workforce

The starting point for information sharing at the local level is a competent workforce. Training those who are charged with disease surveillance and biosurveillance activities is at the core of the development of a competent workforce. A federally sponsored training program for the disease surveillance and biosurveillance workforce is necessary to ensure staff is adequately trained to perform their job tasks at a high level of efficiency and effectiveness. This training should include basic epidemiological concepts, including: disease concepts and definitions; data collection and analysis concepts, as well as, system functionality; and the importance of information sharing. In addition to training existing personnel, highly trained and competent personnel should be recruited to fill new positions and vacancies in the public health and medical enterprise. A trained and competent workforce increases the validity and reliability of the data collected as well as the information that is shared between sectors and jurisdictions, thereby creating better situational awareness and common operating picture.

Once the workforce is trained, it is also important to retain a competent workforce to ensure sustained high quality information sharing. Retention of a highly trained competent workforce is directly associated with the ability to provide adequate compensation and continuing education. Therefore, it is necessary that the public health and medical enterprise have adequate funding to dedicate to this endeavor. Increased federal funding is one such mechanism to ensure this is achieved.

b. Funding and Resources

The LEAPS model strategy section includes a funding and resource component, as this ensures the continued maintenance and improvement of existing

systems and the development of new technologies and mechanisms to facilitate information sharing. Federal level funding has been the impetus for the development and sustainment of most disease surveillance and biosurveillance systems. Federal level funding must be maintained in order to preserve the current level of information sharing and build the capacity to improve information sharing in the public health and medical enterprise. Federal incentives for information sharing are also an important factor in improving information sharing and to prompt entities to share information with others. Most local level disease surveillance and biosurveillance efforts are funded by federal funds, if this funding continues to decrease or completely disappears, these existing systems will languish and eventually become non-existent. Continued federal funding and resources provide the local level with the opportunity to continue to develop and improve the existing infrastructure and workforce to improve information sharing and to create better situational awareness and common operating picture.

c. Infrastructure

The LEAPS model acknowledges that the existing disease surveillance and biosurveillance infrastructure forms the basis of the local level disease surveillance and biosurveillance activities. Most existing systems operate independently of one another, which does not facilitate information sharing between jurisdictions within the public health and medical enterprise. In order for the public health and medical enterprise to improve information sharing across jurisdictions and sectors to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and common operating picture, investments and improvements must be made in the existing infrastructure. Additionally, investments must be made to connect the various pieces of this infrastructure and to develop new technologies to facilitate information sharing across jurisdictions and sectors. This will build capacity at the local level, where information sharing begins, and can encourage collaboration and coordination among the various stakeholders to smooth the progress of information sharing.

3. Collaboration and Coordination

Improving information sharing within the public health and medical enterprise requires a collaborative effort. As such, the LEAPS model proposes that federal leadership must guide this collaborative effort and foster stakeholder buy-in at all levels of the enterprise. Stakeholder buy-in is essential for improving information sharing. This allows for the development of a shared vision and mission, as well as a shared understanding of the information needs, what information can be shared, mechanisms that can be used to facilitate information sharing, and an overall understanding of the larger purpose and goal of information sharing.

The coordination of information-sharing activities should begin at the federal level and be a collective effort from the federal level to the local level, including the private sector. A federally developed plan or framework, such as the LEAPS model for the public health and medical enterprise to improve information sharing could serve as the impetus and guide for the collaborative effort by outlining leadership, policy, strategy, and mechanisms to achieve improved information sharing to create better situational awareness and a common operating picture.

D. CONCLUSION

The primary focus of this chapter was upon the public health and medical enterprise and how information sharing can be improved to create better situational awareness and common operating picture. The conceptual model developed in this chapter focuses upon three elements to improve information sharing—leadership, policy, and strategy—and offers a means by which to achieve those elements.

Figure 1 provides a graphic representation of the LEAPS model and shows how each component is interrelated and connected. Federal leadership is the foundation of the LEAPS model, followed by policy and strategy. Policies must be enforced and developed to facilitate information sharing. Additionally, a strategy must be identified to guide the overall process, which includes standards, building capacity, and collaboration and coordination. The LEAPS model provides a solid foundation for the public health and medical enterprise to improve information sharing across jurisdictions and sectors to

more rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and common operating picture.

Figure 1. LEAPS Model

THIS PAGE INTENTIONALLY LEFT BLANK

VII. RECOMMENDATIONS

This thesis developed the LEAPS model, a conceptual framework that identifies collaborative leadership governed at the federal level, policy, and strategy as key enablers to facilitate the information-sharing process. This chapter will outline specific recommendations for achieving concepts contained in the LEAPS model to improve information sharing.

A. THE LEAPS MODEL

- **Collaborative Leadership**
  - Foster collaborative leadership between the Centers for Disease Control and Prevention and the Department for Homeland Security through the NBAS (National Biosurveillance Advisory Subcommittee) and the NBIS (National Biosurveillance Integration System), with the DHS being the overall governing body for the larger biosurveillance initiative.
  - The DHS and CDC should also collaborate with other stakeholders in the private sector, local and state agencies to identify, set, and enforce policy and strategy to improve information sharing.
- **Policy**
  - Educate stakeholders on HIPAA (Health Insurance Portability and Accountability Act) of and HITECH Act[4] using a standardized national-level education program, versus the numerous methods and programs that presently exist.
  - Develop and implement a new Presidential Directive that identifies DHS as the lead agency over the larger biosurveillance initiative, in close collaboration with the CDC for the human biosurveillance aspects.
- **Strategy**: Create one national strategy based upon the LEAPS model that incorporates the specific recommendations within this chapter, as well as many of

[4] "The HITECH Act recently amended HIPAA by expanding its reach, strengthening certain aspects of the regulations, and increasing federal enforcement tools" (Goldstein & Rein, 2010).

the concepts that currently exist in the *National Health Security Strategy* (HHS, 2009) and the *National Biosurveillance Strategy for Human Health* (CDC Biosurveillance Coordination Unit, 2010). This strategy will address the items as identified in the proposed LEAPS model and should serve as the single strategy for improving information sharing across jurisdictions and sectors to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture.

- **Evaluation and Testing:**
  - The strategy should outline a process to identify and establish an interagency working group to develop, implement, and administer the evaluation and testing component of the LEAPS model strategy, to evaluate and test existing systems as well as emerging technologies.
- **Standards Identification and Development:** Implement the LEAPS model that recommends the creation of a single standard set, to establish minimum standards for detection algorithms, data and information exchange, by combining existing standards when applicable and the creation of new standards when necessary.
  - Detection Algorithms—The International Society for Disease Surveillance should identify best practices and set forth recommendations, which will be incorporated into the LEAPS model strategy to set the minimum standards for detection algorithms for syndromic surveillance.
  - Data and Information Exchange Standards—The PHIN (Public Health Information Network), meaningful use, and the HITSP (Health Information Technology Standards Panel) Biosurveillance Interoperability Specification standards should be incorporated into the LEAPS model as the minimum acceptable standards for data and information exchange.

- **Standardized Content and Definitions:** The LEAPS model recommends the combination of existing standards and definitions into a single standard set that establishes minimum standards for data definitions and ensures continuity and consistency of data collection. Recommendations are listed below.
    - Case Definitions—The Council for State and Territorial Epidemiologists (CSTE) and CDC case definitions for public health surveillance should be incorporated into the LEAPS model strategy as the standard case definitions for public health surveillance and disease reporting.
    - Syndrome Definitions—The definitions contained in the Draft *PHIN Messaging Guide for Syndromic Surveillance* should be included in the LEAPS model strategy as the standard syndrome definitions for syndromic surveillance.
    - The *National Biosurveillance Strategy for Human Health* defines situational awareness as: "the perception of elements in the environment within a volume of time and space, the comprehension of their meaning, and the projection of their status in the near future" (CDC Biosurveillance Coordination Unit, 2010,p. 11).
    - HSPD 21 defines biosurveillance as:

      The process of active data-gathering with appropriate analysis and interpretation of biosphere data that might relate to disease activity and threats to human or animal health—whether infectious, toxic, metabolic, or otherwise, and regardless of intentional or natural origin—in order to achieve early warning of health threats, early detection of health events, and overall situational awareness of disease activity. (White House, 2008, p. 1)
    - A definition for common operating picture in the context of the public health and medical enterprise does not exist; therefore, the *Emergency Management Principles and Practices for Health Care Systems* definition is recommended. It defines common operating picture as: "a broad view of the overall situation as reflected by

situation reports, aerial photography, and other information and intelligence" (The Institute for Crisis, Disaster, and Risk Management [ICDRM], 2006).

- **Levels of Access:** Implement the LEAPS model that recommends levels of access follow generally accepted practices that currently exist within the public health and medical enterprise. This would establish tiered, role-based levels of access based upon area of responsibility, granting access to aggregate data to certain levels to facilitate situational awareness and common operating picture. See Figure 2.

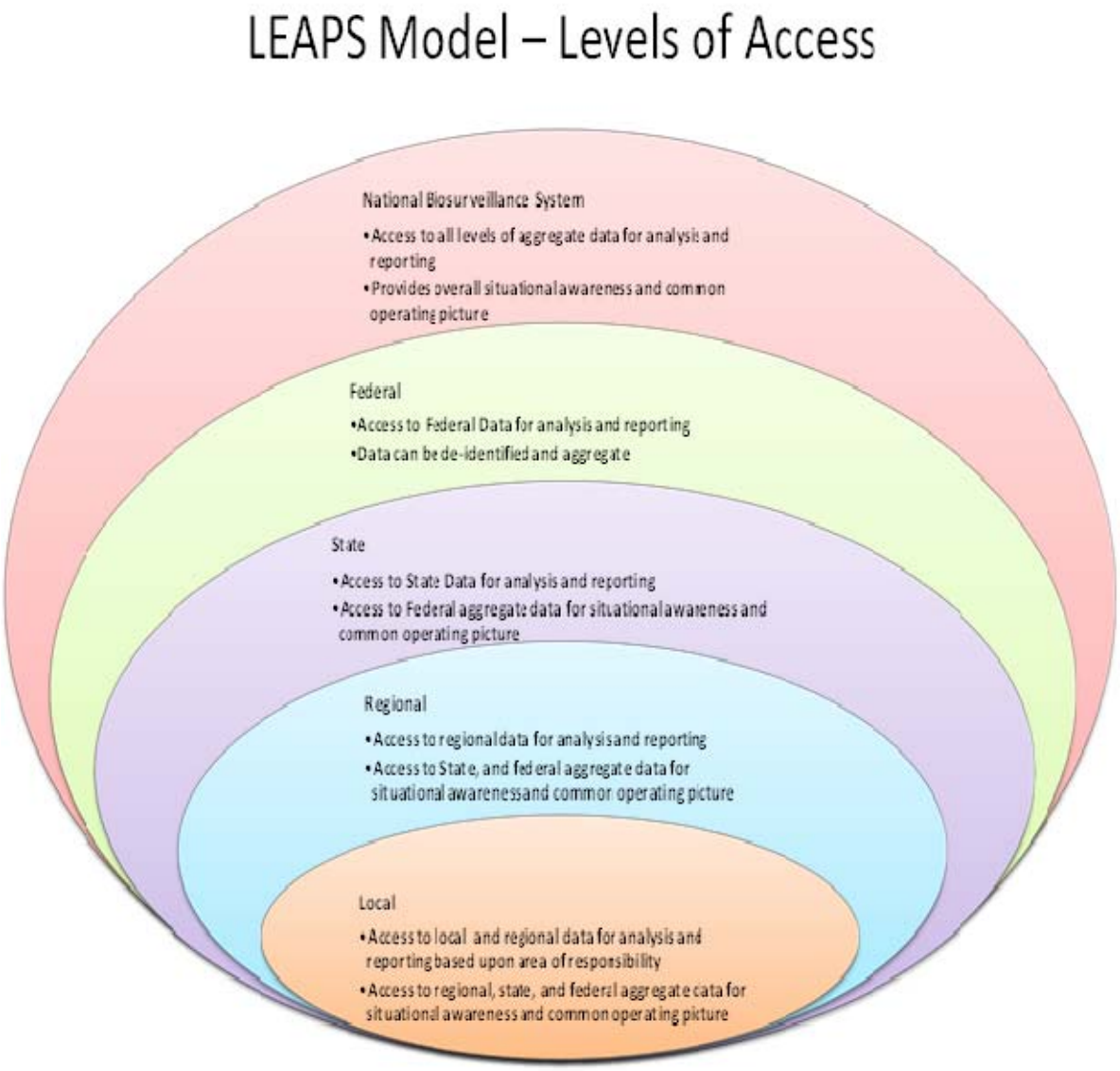

Figure 1. LEAPS Model—Levels of Access

- **Building Capacity**: The LEAPS model strategy includes three components for building capacity: competent workforce, funding and resources, and infrastructure. These components are also included as part of the *National Health Security Strategy* (HHS, 2009) and the *National Biosurveillance Strategy for*

Human Health (CDC Biosurveillance Coordination Unit, 2010). The LEAPS model supports the general recommendations of both of these strategies; however it offers specific actions to build capacity.

- **Competent Workforce**
  - The LEAPS model recommends the implementation of a federally developed training and education program and standards for the existing and future workforce. A comprehensive training curriculum should be developed to include basic epidemiological principles, biosurveillance principles, basic information-sharing education, as well as statistical analysis and education on the functions of the various systems used to facilitate the information-sharing process.
- **Funding and Resources**
  - Sustained funding for building capacity is critical to improving information sharing within the public health and medical enterprise. This funding should be administered through the DHS and distributed to stakeholders at all levels.
- **Infrastructure**
  - The LEAPS model recognizes that to continue to improve information sharing, efforts must be made to sustain and maintain existing infrastructure and build new infrastructure through sustained funding and resources.
  - Infrastructure similar to the New York Health Commerce System Platform could be used as a small-scale model for an integrated system architecture.

- **Collaboration and Coordination**
  - The LEAPS model recommends the encouragement of collaboration and coordination through funding of collaborative efforts to improve information sharing.

- The LEAPS model recognizes that the collaborative effort to improve information sharing must start at the federal level and should use the federal level policy and strategy to guide the collaboration effort

B. SUMMARY

Federal governance is the foundation of the LEAPS model. It must be present in order to realize the other two pieces—policy and strategy. Improving information sharing hinges upon federal level governance to identify and enforce policy, as well as, develop an overarching federal strategy to enhance the ability of the public health and medical enterprise, to share information across jurisdictions to rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and a common operating picture.

THIS PAGE LEFT INTENTIONALLY BLANK

VIII. CONCLUSION

> *Containing the spread of disease or responding to other human health hazards in an interconnected world requires active vigilance for signs of an adverse public health event, rapid validation of its presence, and swift characterization so that resources and adaptive strategies can be employed effectively. Greater information sharing and strengthened collaborations among public health, healthcare, environmental, animal and plant health communities along with partnerships with private sector organizations addressing common goals can unleash the power of health-related information to prevent, protect, and mitigate the health threats and hazards that Americans face* [emphasis added]. (CDC Biosurveillance Coordination Unit, 2010)

A. IMPROVED INFORMATION SHARING IS NECESSARY

The need for the public health and medical enterprise to share information has increased over the last decade. Events such as the Severe Acute Respiratory Syndrome (SARS) outbreak, natural disasters, such as Hurricane Katrina, the 2009 H1N1 influenza outbreak, and other naturally occurring outbreaks, such as the recent Shiga toxin-producing *E. coli* O104 (STEC O104:H4) infections occurring in and associated with travel to Germany "have highlighted the need for real-time information exchange to enhance government's awareness and understanding of public health events in order for the government to prevent or respond to situations as they unfold" (Rolka, O'Connor, & Walker, 2008). In addition to the threats increasing over the past decade, there has been an influx of policies and strategies, related to improving information sharing, within the public health and medical enterprise and the larger homeland security enterprise, including HSPDs 9, 10, and 21, PAHPA, and the Implementing Recommendations of the National Commission on Terrorist Attacks upon the United States Act of 2007, the *National Health Security Strategy*, and the *National Biosurveillance Strategy for Human Health*. A significant amount of attention has been, and will continue to be, given to improving information sharing within the public health and medical enterprise. Great strides have been made; however, there is still a significant amount that can be done to improve information sharing and these improvements must be made before we can begin to integrate systems for a national biosurveillance enterprise.

B. THE WAY FORWARD

This thesis set out to determine whether a national integrated biosurveillance enterprise can improve information sharing for situational awareness and common operating picture, including outlining who should supply the data, how the data should be shared, and recommendations for how to integrate the disparate systems that presently exist.

This research identified a significant amount of barriers to information sharing; however, it also identified ways to address and overcome those barriers. Many promising initiatives were discussed including the move to electronic health records, health information exchanges, and meaningful use. These initiatives offer a mechanism to enable information sharing between and among entities and jurisdictions that is not overly burdensome upon any one entity. These are technological advances or "systems" that can facilitate information sharing; however, as noted in this research, there are more basic things that must occur.

1. LEAPS Model

The LEAPS model was developed in this thesis to serve as a conceptual framework to guide the process to improve information sharing through the development of a strong foundation centered upon leadership, policy, and strategy. It is rooted in a collaborative leadership structure with a single federal entity appointed to lead the initiative. The overall mission of this leader is the development, identification, and enforcement of policy, and to drive the strategy for improving information sharing. The LEAPS model strategy includes standards, capacity building, and encourages collaboration and coordination, which are the basis for a solid information-sharing foundation.

2. Limitations and Further Research

This research provides only a glimpse of information sharing within the public health and medical enterprise. This research did not set out to be a total review of the public health and medical enterprise and current information-sharing practices. It was

meant to give a broad-based view of the some of the ways that information sharing may be improved to more rapidly detect and respond to naturally occurring or intentional disease outbreaks or exposures and to create better situational awareness and common operating picture. There has been and continues to be a great deal of research related to information sharing and biosurveillance. The case studies and interviews presented here were a small, but representative sample of the vast amount of literature and professionals available. There is further research that must be done to construct an integrated national biosurveillance enterprise including that necessary to specify details about: 1) what data is needed; 2) who should supply the data; and 3) how existing systems should be integrated. This may be accomplished through a more in-depth analysis of existing literature along with a more extensive interview process that includes a larger sample of interviewees. In addition, research should be conducted to measure the success of current initiatives, identify best practices, as well as to identify future actions to improve information sharing. This research and much of the literature identified a general lack of science base in regard to information sharing within the public health and medical enterprise and regarding biosurveillance. Research should be conducted in these areas to build and expand the overall knowledge base.

3. Further Application

The LEAPS model developed in this research may have a broader application above and beyond public health information sharing. The basic premise of this model, a strong foundation, is paramount to improving information sharing within any field and any context, including those on a more global level, and within law enforcement and the intelligence communities.

THIS PAGE INTENTIONALLY LEFT BLANK

LIST OF REFERENCES

Centers for Disease Control and Prevention. (2010). Investigation update: Multistate outbreak of human salmonella enteritidis infections associated with shell eggs. Retrieved July 30, 2010, from http://www.cdc.gov/salmonella/enteritidis/

Centers for Disease Control and Prevention Office of Public Health Preparedness and Response Biosurveillance Coordination Unit. (2010). *National biosurveillance strategy for human health*. Washington, DC: U.S. Department of Health and Human Services.

Centers for Disease Control and Prevention. Disease surveillance system efforts: Emergency preparedness and response, United States House of Representatives, (2003).

Epidemiology Unit, Ministry of Health. (2005). Surveillance case definitions for notifiable diseases in Sri Lanka. Sri Lanka: Epidemiology Unit, Ministry of Health.

Goldstein, M. M. & Rein, A. L. (2010). Data segmentation in electronic health information exchange: Policy considerations and analysis. Washington, DC: Office of the National Coordinator for Health IT.

Gotham, I. J., Le, L. H., Sottolano, D. L., & Schmidt, K. J. (2008). Public health preparedness informatics infrastructure. A case study in integrated surveillance and response: 2004–2005 national influenza vaccine shortage. Proceedings Biosurveillance and Biosecurity International Workshop, BioSecure 2008. Raleigh, NC. Berlin/Heidelberg: Springer. doi:10.1007/978-3-540-89746-0_5

Grotto, A. J., & Tucker, J. B. (2006). *Biosecurity: A comprehensive action plan.* Washington, DC: Center for American Progress.

Henderson, Joseph M. CDC's Disease Surveillance System Efforts: Emergency Preparedness and Response, United States House of Representatives, (2003).

Homeland Security Presidential Directive 21: *Public health and medical preparedness*. (2008). Retrieved August 15, 2010, from http://www.dhs.gov/xabout/laws/gc_1219263961449.shtm

Institute for Crisis, Disaster and Risk Management, George Washington University. (2006). *Emergency management principles and practices for healthcare systems*. Washington, DC: Veterans Health Administration and U.S. Department of Veterans Affairs.

Institute of Medicine and National Research Council. (2011). *BioWatch and public health surveillance: Evaluating systems for the early detection of biological threats.* Abbreviated version. Washington, DC: National Academies Press.

Jenkins, W. O., Laffoon, A., Cooper, M., Dowdle, C., Godfrey, K., & Yohe, A. (2009). *Biosurveillance: Developing a collaboration strategy is essential to fostering interagency data and resource sharing* (No. GAO-10-171). Washington, DC: Government Accountability Office.

Jenkins, W. O., Laffoon, A., Cooper, M., Godfrey, K., Krause, A., Banovac, S., & Kuebler, S. (2010). *Biosurveillance: Efforts to develop a national biosurveillance capability need a national strategy and a designated leader* (No. GAO-10-645). Washington, DC: Government Accountability Office.

Kant, L. & Krishnan, S. K. (2010). Information and communication technology in disease surveillance, India: A case study. *BMC Public Health*. doi:10.1186/1471-2458-10-S1-S11

Leedy, P. D. & Ormrod, J. E. (2005). *Qualitative research: Practical research* (8th ed.). Upper Saddle River, NJ: Pearson Merrill Prentice Hall.

National Security Telecommunications Advisory Committee. (2003). Legislative and Regulatory Task Force Report: Barriers to information sharing. Washington, DC: author.

Program Manager, Information Sharing Environment. (2009). *Information sharing environment: progress and plans annual report to the Congress*. Washington, DC: author.

Regional Office for South-east Asia, World Health Organization. (2003). *Regional strategy for integrated disease surveillance: Report of an intercountry consultation Yangon, Myanmar, 21–24 August 2002*. New Delhi: author. Retrieved March 6, 2011. from http://www.searo.who.int/LinkFiles/Publication_130_RSI-Disease-Surveillance.pdf

Regional Office for South-east Asia, World Health Organization. (2004). *Comprehensive assessment of national surveillance systems in Sri Lanka: Joint assessment report 4-13 March 2003*. New Delhi: author. Retrieved March 6, 2011, from http://www.searo.who.int/LinkFiles/Publication_Comprehensive_assessment__NSS_Srl.pdf

Rolka, H., O'Connor, J. C., & Walker, D. (2008, December 2). Public health information fusion for situation awareness. In D. Zeng, H. Chen, H. Rolka & B. Lober (Eds.), Proceedings Biosurveillance and Biosecurity International Workshop, BioSecure 2008 (pp. 1, 2, 9). Raleigh, NC. Berlin/Heidelberg: Springer. doi: 10.1007/978-3-540-89746-0_1

Strauss, A. C. & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.

Sutton, V. P. J. D. (2002). *Legal impediments to surveillance for biological threats and countering terrorism*. Albuquerque, NM: Unifed Science & Technology for Reducing Biological Threats & Countering Terrorism.

Toner, E. S. (2009). *Creating situational awareness: A systems approach*. Pittsburgh, PA: Center for Biosecurity, University of Pittsburgh Medical Center.

United Nations Economic and Social Commission for Asia and the Pacific. *Local government in Asia and the Pacific: Country paper: Sri Lanka.* Retrieved March 6, 2011, from http://www.unescap.org/huset/lgstudy/country/srilanka/srilanka.html

United States Department of Defense. (2009). *Instruction: National Center for Medical Intelligence*. Washington, DC: author.

United States Department of Health and Human Services. (2010). Draft biennial implementation plan for the National Health Security Strategy for the United States of America. Washington, DC: author.

United States Department of Health and Human Services. (2009). *National Health Security Strategy of the United States of America.* Washington, D.C.: author.

United States Department of Justice. (2005). *Law enforcement information sharing program*. Washington, DC: author.

Uscher-Pines, L., Farrell, C. L., Babin, S. M., Cattani, J., Gaydos, C. A., Hsieh, Y., & Rothman, R. E. (2009). *Framework for the development of response protocols for public health syndromic surveillance systems: Case studies of 8 US states*. Disaster Medicine and Public Health Preparedness. doi:10.1097/DMP.0b013e31819f4483

Waidyanatha, N. (2010). *Beyond the century old disease surveillance and notification in Sri Lanka*. Retrieved March 6, 2011, from http://lirneasia.net/2010/04/rtbp-kuru-alert-exer/

Waidyanatha, N., M., G., Weerakoon, P., Gow, G., Sabhnani, M., & Dubrawski, A. (2010). *Real-time biosurveillance pilot in India and Sri Lanka* (pp. 367–373). 2010 12th IEEE International Conference on e-Health Networking Applications and Services, July 1–3, 2010, Lyon France. doi:10.1109/HEALTH.2010.5556543

World Health Organization. (2011). International Health Regulations (IHR). Retrieved March 5, 2011, from http://www.who.int/ihr/en/

INITIAL DISTRIBUTION LIST

1. Defense Technical Information Center
   Ft. Belvoir, Virginia

2. Dudley Knox Library
   Naval Postgraduate School
   Monterey, California