IMPROVING LOCAL PUBLIC HEALTH CAPACITY THROUGH A HEALTH INFORMATION EXCHANGE IN SOUTH TEXAS: POLICY IMPLICATIONS FOR HEALTH LEADERS

Saad Khan

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

Chapel Hill
2014

Approved by:

Christopher M. Shea
Suzanne H. Hobbs
George H. Pink
Niek S. Klazinga
Hank Fanberg
ABSTRACT

Saad Khan: Improving Local Public Health Capacity Through a Health Information Exchange in South Texas: Policy Implications for Health Leaders
(Under the direction of Christopher M. Shea)

Three out of four deaths in the state of Texas are caused by chronic diseases with hospital discharges in 2008 alone costing more than $10 billion. Chronic disease surveillance systems are needed for the identification and tracking of diseases in order to target prevention and treatment activities. However, the IOM has reported inconsistencies in surveillance of chronic illnesses caused by a lack of standardized methods for measuring complex attributes and determinants of health along with insufficient public health system resources to perform this function.

The use of health information exchanges (HIE) offer important new and rich potential data sources for public health to improve our ability to monitor and track chronic diseases. But the ability of public health agencies to manage and act on these new electronic data streams has been identified as a challenge due to their limited current capacities.

This study aimed to understand the challenges in using HIE for community level surveillance of chronic diseases and reviewed the capacity of public health departments participating in a Corpus Christi based HIE, Health Information Network of South Texas (HINSTX). The study used a qualitative approach that combined a survey of health departments and semi-structured key informant interviews of health department, state, and national officials to supplement and provide context for survey data.

Three key themes were identified: need for skilled staff; clearly articulated regulations to enable effective use of HIE; and development of an integrated public health IT strategy.
Recommendations included, personnel capacity development, inter-organizational informatics collaboration, interim legal bridge for using HIE for public health surveillance and health department enterprise architecture plan development.
To my father, Nazakat Ali Khan who taught me the value of knowledge over wealth and to my mother, Sualeha Khan who urged me to selflessly do for those who cannot do for themselves. I miss you both dearly.
ACKNOWLEDGEMENTS

The seemingly never ending journey to the doctoral finish line has finally arrived. I’m amazed and glad that it’s over and I have many to thank for helping me get here.

I want to thank my committee chair, Dr. Chris Shea, for guiding me along the research process, providing invaluable insights, and nudging me along the way. I also want to thank the other members of my committee, Mr. Hank Fanberg, Dr. Sue Hobbs, Dr. Niek Klazinga, and Dr. George Pink who provided in depth comments and helped me hone the message. I especially want to thank Hank for the opportunity, as I was just a cold caller who was looking for a HIE to study and he graciously volunteered himself and his organization—I couldn’t have done it without your support and friendship.

I am also indebted to the dedicated public health officials from Nueces County and Health Service Region Eleven, as well as officials from the Texas Health Services Authority, Texas eHealth Alliance, and HHS’s Office of the National Coordinator who formed the foundation for this study and without whom this study would not have been possible.

To my Cohort Seven gang, thanks for letting me play ‘That Guy’ for C7. I hope brown will never be the same for you, the Eifel Tower is more than just a monument in Paris, and you’ll use WWSD as one of your analysis methods in the future. Your brilliance, support, and encouragement dragged me through and I am lucky to call you my friends.
To two very special women, Anam Ahmad and Hibah Qudsi, a huge thanks. Your research and administrative support made all the difference when I was overwhelmed and made it possible for me to cross the finish line sooner than I could have ever imagined. I am blessed and proud to have you as my nieces.

Thank you to my children, Amani, Hamiz, Aarim, and Rameesa for your pure love and understanding of my time away to complete my work. Dad’s back and ready to try and make up for lost time.

Above all, I would like to thank my wife Aisha. Your support, patience, space and undying love have been the backbone of not only the past three years but of our seventeen years together. While I’ve tested your tolerance to deal with my wild ambitions, endless meanderings, and downright nuttiness, you’ve shown me over and over your tireless compassion and love. Most of all, you are my best friend and I owe you everything.
TABLE OF CONTENTS

LIST OF TABLES .................................................................................................................. x

LIST OF FIGURES ............................................................................................................... xi

LIST OF ABBREVIATIONS ................................................................................................. xii

CHAPTER 1: INTRODUCTION ............................................................................................. 1

Problem Statement ............................................................................................................ 1

Background ......................................................................................................................... 2

Purpose, Research Question, and Specific Aims .............................................................. 5

Significance ......................................................................................................................... 5

CHAPTER 2: LITERATURE REVIEW .................................................................................. 8

Literature Review Methods ............................................................................................... 9

Results ............................................................................................................................... 14

Discussion ......................................................................................................................... 22

Limitations of the Literature ............................................................................................ 26

Gaps and Implications for Research.................................................................................. 27

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY ............................................. 30

Evaluation Framework ....................................................................................................... 30

Research Design ................................................................................................................. 35

Local Setting ....................................................................................................................... 40

Data Collection Plan ......................................................................................................... 43
Data Analysis and Results ......................................................................................................................... 45
LHD Surveys .............................................................................................................................................. 45
Key Informant Interviews ........................................................................................................................... 45
Aim 1 ............................................................................................................................................................. 47
Aim 2 ............................................................................................................................................................. 51
CHAPTER 5: DISCUSSION ......................................................................................................................... 62
Aim 3 ............................................................................................................................................................. 63
Recommendations ......................................................................................................................................... 63
Limitations of the Research ........................................................................................................................ 77
Benefits of the Research ............................................................................................................................ 79
CHAPTER 6: PLAN FOR CHANGE ........................................................................................................... 81
APPENDIX 1 .............................................................................................................................................. 93
APPENDIX 2 .............................................................................................................................................. 99
REFERENCES ........................................................................................................................................... 103
LIST OF TABLES

Table 1 - Key terms and Definitions for Review................................................................. 9
Table 2 - Inclusion/Exclusion Criteria..................................................................................12
Table 3 - Summary of Search Strategy................................................................................13
Table 4 - Article Themes ......................................................................................................15
Table 5 - NPCCN’s sentinel events and target groups .........................................................21
Table 6 - Research Design ..................................................................................................36
Table 7 - Summary of HINSTX service area LHD Review ...............................................42
Table 8 - Key People, Process, and Technology Attributes ..............................................48
Table 9 - Themes from Informant Interviews ....................................................................53
Table 10 - Summary of Themes, Gaps, Informant Quotes, and Key Recommendations ....66
Table 11 - Recommendations and Plan for Change..............................................................86
LIST OF FIGURES

Figure 1 - Generic depiction of chronic disease surveillance process flow..........................33
Figure 2 - Map of Texas Health Service Regions.........................................................................41
Figure 3 - Ideal balance of people and technology inputs into public health surveillance...........65
## LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1c</td>
<td>glycated hemoglobin</td>
</tr>
<tr>
<td>ARRA</td>
<td>American Recovery and Reinvestment Act of 2009</td>
</tr>
<tr>
<td>ASTHO</td>
<td>Association of State and Territorial Health Officials</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
</tr>
<tr>
<td>CQM</td>
<td>clinical quality measures</td>
</tr>
<tr>
<td>DSHS</td>
<td>Texas Department of State Health Services</td>
</tr>
<tr>
<td>EA</td>
<td>enterprise architecture</td>
</tr>
<tr>
<td>ED</td>
<td>emergency department</td>
</tr>
<tr>
<td>EHR</td>
<td>electronic health record</td>
</tr>
<tr>
<td>EMR</td>
<td>electronic medical record</td>
</tr>
<tr>
<td>FTE</td>
<td>full-time equivalent</td>
</tr>
<tr>
<td>FY</td>
<td>fiscal year</td>
</tr>
<tr>
<td>GAO</td>
<td>Government Accountability Office</td>
</tr>
<tr>
<td>HEDIS</td>
<td>Healthcare Effectiveness Data and Information Set</td>
</tr>
<tr>
<td>HHS</td>
<td>United States Department of Health and Human Services</td>
</tr>
<tr>
<td>HHSC</td>
<td>Texas State Health and Human Services Commission</td>
</tr>
<tr>
<td>HIE</td>
<td>health information exchange</td>
</tr>
<tr>
<td>HINSTX</td>
<td>Health Information Network of South Texas</td>
</tr>
<tr>
<td>HIO</td>
<td>health information organization</td>
</tr>
<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act of 1996</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Form</td>
</tr>
<tr>
<td>---------</td>
<td>-----------</td>
</tr>
<tr>
<td>HIT</td>
<td>health information technology</td>
</tr>
<tr>
<td>HITECH</td>
<td>Health Information Technology for Economic and Clinical Health Act of 2009</td>
</tr>
<tr>
<td>IOM</td>
<td>Institute of Medicine</td>
</tr>
<tr>
<td>IT</td>
<td>information technology</td>
</tr>
<tr>
<td>LHD</td>
<td>local public health department</td>
</tr>
<tr>
<td>LIMS</td>
<td>laboratory information management system</td>
</tr>
<tr>
<td>NACCHO</td>
<td>National Association of County and City Health Officials</td>
</tr>
<tr>
<td>NCQA</td>
<td>National Committee for Quality Assurance</td>
</tr>
<tr>
<td>NEDSS</td>
<td>National Electronic Disease Surveillance System</td>
</tr>
<tr>
<td>NPCCN</td>
<td>The Northern Piedmont Community Care Network</td>
</tr>
<tr>
<td>NPHPSP</td>
<td>National Public Health Performance Standards Program</td>
</tr>
<tr>
<td>NwHIN</td>
<td>Nationwide Health Information Network</td>
</tr>
<tr>
<td>ONC</td>
<td>Office of the National Coordinator for Health Information Technology</td>
</tr>
<tr>
<td>PHII</td>
<td>Public Health Informatics Institute</td>
</tr>
<tr>
<td>PHIN</td>
<td>Public Health Information Network</td>
</tr>
<tr>
<td>PHR</td>
<td>personal health record</td>
</tr>
<tr>
<td>THSA</td>
<td>Texas Health Services Authority</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
CHAPTER 1: INTRODUCTION

Problem Statement

Chronic diseases such as cancer, diabetes, and heart disease have become the leading causes of death and disability around the globe (World Health Organization [WHO], 2005). In the United States, 133 million Americans are affected by these chronic diseases which are responsible for seven out of ten deaths in the US (Centers for Disease Control and Prevention [WHO], 2012). For example, more than 25 million Americans already have diabetes, and another 79 million are pre-diabetic. Nearly 2 million more new cases are diagnosed annually (American Diabetes Association, 2012). The trend has had a substantial impact on US health care and economic costs. In 2007, diabetes alone generated over $115 billion in direct medical costs and almost $60 billion in indirect costs including disability, work loss, and premature mortality (CDC, 2011).

Mirroring national trends, three out of four deaths in the state of Texas are caused by these chronic diseases. Heart disease, malignant neoplasms, chronic lower respiratory disease, and strokes are the top four causes of death. By themselves, heart disease, cancer, and stroke, account for over 50 percent of the annual deaths in Texas (Texas Department of State Health Human Services, 2010). The economic impacts have been substantial as well. Hospital discharges in 2008 for heart disease, cancer, and stroke care cost more than $10 billion. Similarly, direct treatment expenditures related to diabetes in 2003 alone were almost $3.7 billion, with another estimated 66,000 hospital admissions generated by cardiovascular disease
attributed to diabetes (Texas Department of State Health Human Services, 2008). It is clear that the number of individuals impacted and the associated consequences are substantial and urgent action is needed.

**Background**

The identification and tracking of the spread of chronic diseases is imperative in order to target prevention and treatment activities. Public health surveillance systems are needed to inform public health officials, clinicians, policy makers, and the public about approaches to disease management. As defined by the Centers for Disease Control (CDC), “Public health surveillance is the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health” (CDC, 2001). For public health, surveillance means identifying and engaging in health promotion and disease prevention activities targeting the major risk factors for disease in the community.

However, the Institute of Medicine (IOM) has reported inconsistencies in surveillance of chronic illnesses. These inconsistencies are caused by a lack of standardized methods for measuring complex attributes and determinants of health, as well as insufficient resources to perform this function. Furthermore, the IOM has noted that public health systems lack the capacity to effectively take action based on surveillance activities (Institute of Medicine [IOM], 2012). Desai et al. (2003) have echoed that current surveillance systems face key challenges such as maintaining and expanding surveillance capacity, identifying and assessing specific populations and indicators, improving existing data sources, and reporting and increasing the use of the surveillance data obtained. In addition, the current surveillance systems are insufficient for tracking and monitoring trends in the US overall or even within specific communities.
The expanded use of health information technology (IT), triggered in part by recent legislation, including but not limited to Electronic Health Record systems (EHR), offers important new and rich potential data sources to improve our ability to monitor and track diabetes, prevention and care activities. Health Information Exchanges (HIE) in particular offer one of the newest emerging opportunities for public health. Health Information Exchanges are commonly facilitated by third party entities that provide organizational structure, governance, leadership and technical support; and include a range of community stakeholders such as hospitals, ambulatory care offices, labs, pharmacies, and payers (Healthcare Information and Management Systems Society [HIMSS], 2009).

Health Information Exchanges (HIEs) can serve as critical community partners for public health agencies and make readily available a broad set of data cutting across multiple settings. Health Information Exchanges also serve as a neutral convener across what would typically include many competitors and provide the geographic coverage and subsequent volume of population data otherwise not possible (Hill et al., 2007). As such, HIEs have the potential to provide valuable information for chronic disease surveillance and to improve communication for health promotion, prevention and treatment activities.

While the potential benefits for public health’s engagement in HIEs appears reasonable and indeed a boon for enhancing population health tracking capabilities, few public health agencies are active HIE partners today. In a survey of HIEs and public health agencies in the US, Hessler et al. (2009) found very few public health agencies currently exchanging data with an HIE organization. Also, a search of PubMed in August 2014, using the search string, “health information exchange” AND “public health”, returned only 103 citations, indicating that the literature in the field is still maturing.
Providing a major stimulus for growing public health interest in HIEs, the “Health Information Technology for Economic and Clinical Health Act” (HITECH) provisions within the American Recovery and Reinvestment Act of 2009 (ARRA) provided more than $35 billion in funding for nationwide provider adoption and “meaningful use” of interoperable health information technology like EHRs and HIE. Importantly, “meaningful use” sets specific objectives, including those for population health, which must be met by providers in order to receive incentive payments. Several core criteria for “meaningful use” require electronic information exchange and public health engagement by providers including, electronic data submission to immunization registries, electronic data submission on reportable diseases, and electronic syndromic surveillance data submission, as well as several Clinical Quality Measures (CQM) such as those for chronic conditions (United States Department of Health and Human Services [HHS], 2013; Centers for Medicare & Medicaid Services [CMS], 2003). However, the ability of public health agencies to manage and act on these new electronic data streams has been identified as a challenge due to their limited capacities to meet current demands (Desai et al., 2003; CDC, 2014). Additional challenges include the lack of agreed upon data standards on not only public health surveillance processes but also for clinical care delivery, as the source systems. Health departments must also then provide better timely actionable feedback loops to both educate and guide clinical and other community stakeholders to prevent and control chronic diseases. Critically, public health personnel will need to adapt to the electronic health information transition by acquiring new, interdisciplinary skills in the areas of informatics, information technology, and quality improvement (Maylahn et al., 2013).
Purpose, Research Question, and Specific Aims

This study was done to evaluate the capacity of local public health departments (LHD) participating in a Corpus Christi, Texas based HIE, Health Information Network of South Texas (HINSTX) for community level monitoring and tracking of chronic diseases. The overarching research question was:

*How can local public health departments participating in the Health Information Network of South Texas (HINSTX) best use HIE to support community level chronic disease surveillance?*

The specific aims included:

1. To assess the gaps in current surveillance capacity to manage the potential new data streams including available staffing, processes, IT support, and others.
2. Identify the barriers and facilitators to closing the gaps in community level chronic disease monitoring and tracking capacity.
3. Develop strategies to help guide the filling of gaps in local health department’s surveillance capacity.

**Significance**

The growing care and economic burden of chronic diseases imposes significant challenges, not only to the nation as a whole, but to the individuals and communities that feel the day to day effects of living with these diseases. The risk factors for such conditions, including sedentary lifestyles, obesity, tobacco use, and others are well understood. Additionally, both clinical and public health interventions to manage these illnesses, such as targeted treatments, prevention campaigns and new food labelling, are proving effective strategies for improving future outlook. For these interventions to be applicable, the disease prevalence must be monitored so as to assess their effectiveness. However, barriers persist in our ability to
effectively manage and monitor chronic disease trends such as fragmented health care systems, a lack of effective action, need for care coordination, and a lack of interoperable information systems.

Against the national backdrop of “wiring” health care, there is an opportune time to study this potential application of public health informatics. Public health informatics has been defined as the systematic application of information and computer science and technology to public health practice, research, and learning (Friede et al., 1995). IOM and others have already highlighted the potential for HIEs to develop and augment chronic disease surveillance and prevention capabilities which were previously impossible (IOM, 2012; Shapiro et al., 2011). However, HIEs and their use for chronic disease and population level monitoring are not well understood.

An evaluation of local public health agencies participating in the Health Information Network of South Texas (HINSTX) surveillance readiness, which brings together regional networks of providers, pharmacists, hospitals, health departments, and other community organizations, offered a unique opportunity to better understand practical challenges, results, and lessons learned from an early stage HIE as its services are still evolving. The evaluation also provided a feedback loop into the project itself and allows the project to make refinements in the data exchange approach and perhaps identify and expose possible unintended consequences of the electronic data exchange (Cusack et al., 2010). In addition, an evaluation of the HIEs provided insights into facilitators and barriers encountered that may help other public health organizations understand how to approach their own projects and potential issues to consider. Finally, HINSTX is also serving as a pilot site for HHS’s Office of the National Coordinator’s (ONC) Nationwide Health Information Network (NwHIN) Direct infrastructure and has offered
an opportunity to provide national visibility for public health capacity requirements in the evolving HIE landscape.

While there are a number of public health use cases for HIE, there are very few that are implemented (Grannis et al., 2006; Rirchards et al., 2006; Barthell et al., 2004) and even fewer for chronic conditions (Lobach et al., 2007). Therefore, given the mounting concern of chronic diseases in Texas and in particular diabetes in South Texas, this study focused the evaluation on measures as they pertain to the ability of local public health departments to effectively make use of new data streams offered by the HIE and leverage the information to improve chronic disease monitoring and tracking across entire communities. It was hypothesized that the HIE will ultimately be a key enabler in the public health process for tracking and monitoring chronic diseases and provide the rapid feedback loops to better target treatment and prevention protocols, but the requisite surveillance capacity may not currently exist in local public health departments to effectively utilize the new information streams.

As noted by the CDC (1999), “program evaluation is an essential organizational practice in public health; however, it is not practiced consistently across program areas”. Moreover, HIE projects in particular have been recognized as a critical step in the national effort to use electronic exchange of health care information to improve patient safety, quality, effectiveness and efficiency of care. But with limited data on impact of HIEs for public health functions, as well as the growing number of projects and funding by federal and state authorities, it is even more important that evaluations be done to better understand future implications (Cusack et al., 2010).
CHAPTER 2: LITERATURE REVIEW

The expanded use of health information technology (IT) offers the potential to improve the quality of care, save money on administrative costs and bolster the public health infrastructure (Walker et al., 2005). In addition, for clinicians, population health-oriented health IT such as, EHRs and HIEs have the potential to reduce the paperwork burden of public health reporting and provide decision support about community-level trends that aid in diagnosis and treatment choice. Similarly, for national and local institutions, automated reporting will reduce paperwork burdens and data input costs as a trend continues toward more reporting requirements while shortening the feedback on population health status allowing better targeting of scarce resources. For the public, population health-oriented EHRs and HIEs offer increased engagement with the health-care system, more ownership of data, and improved health outcomes (Kukafka et al., 2007).

With growing EHR use, HIE has the potential to provide the necessary interconnections to collect, track, and analyze population health measures more efficiently. However, it remains unclear which specific aspects of population health could be improved and more importantly whether public health agencies are prepared to receive, analyze, and act effectively on the potentially voluminous data as adoption and use of HIEs increases. Subsequently, there is an opportunity to explore what types of population health data is currently available in these HIEs and what the state of surveillance readiness of public health agencies is to maximize the use of these health information technologies for public health surveillance.
Literature Review Methods

Search Criteria

This literature review aimed to examine and assess existing scholarly knowledge related to the use of HIE for public health functions, in particular chronic-disease-related surveillance; however, the vast majority of published literature on HIE was in the health services domain. Given the very limited literature available exploring the use of HIEs for population level health monitoring, the results of the literature review served to not only highlight the dearth of studies related to population health but also identified some barriers and challenges for using HIE for public health where studies did exist. Establishing refined selection criteria was the first step in ensuring that any tangential studies were quickly eliminated in the query process. Central to this step was defining the terminologies which have slightly different meanings from source to source. Therefore, the terms and definitions in Table 1 are meant to describe the lens through which all potential literature was viewed for inclusion.

Table 1: Key terms and Definitions for Review

<table>
<thead>
<tr>
<th>Key Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic Health Record (EHR)</td>
<td>An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization. EHR is not distinguished from electronic medical record (EMR) for purposes of this research (National Alliance for Health Information Technology [NAHIT], 2008).</td>
</tr>
<tr>
<td>Health Information Exchange (HIE)</td>
<td>The electronic movement of health-related information among organizations according to nationally recognized standards (NAHIT, 2008)</td>
</tr>
<tr>
<td>Health Information Organization (HIO)</td>
<td>An organization that oversees and governs the exchange of health-related information among organizations according to nationally recognized standards (NAHIT, 2008).</td>
</tr>
<tr>
<td>Health quality</td>
<td>The degree to which health services for individuals and populations</td>
</tr>
<tr>
<td>Table Title</td>
<td>Description</td>
</tr>
<tr>
<td>-------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Health care quality indicators</td>
<td>Provide a quantitative basis for clinicians, organizations, and planners aiming to achieve improvement in care and the processes by which patient care is provided (Mainz, 2003).</td>
</tr>
<tr>
<td>Surveillance</td>
<td>The ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health (IOM, 2012).</td>
</tr>
<tr>
<td>Population health measures</td>
<td><strong>Aggregate:</strong> combine data from individuals, summarized regionally or nationally, as hypercholesterolemia or heart disease rate. <strong>Environmental:</strong> external to the individual, such as air or water quality, but can include individual exposure levels. <strong>Global indexes:</strong> no equivalent at the individual level and includes contextual variables such as policies promoting equity in access to care, or laws restricting smoking in public places (Morgenstern, 1995).</td>
</tr>
</tbody>
</table>

Based on the definitions of terms above, the key criteria for inclusion were studies on the use of HIEs:

A. From a population health perspective with aggregate data level *not* limited to individual or patient specific. It is understood that HIEs by definition will not be good sources for environmental data and even less likely to have global index information.

B. In population-level health measurement/reporting *not* strictly within the confines of patient-level health care quality improvement but at the community aggregate level.

There was no time constraint placed on dates of publication for journal articles. While it is understood that the field of health information technology is rapidly evolving, the basis for this decision hinged on the fact that the concept of HIEs has been around for over two decades, and studies may have been done at any point exploring secondary data uses even if using data that is now outdated.
Only articles written in English were included, but studies did not need to be done in the US. HIEs have been and are being implemented across the globe at national and local levels, in public and private sectors by multi-national vendors and organizations that may provide relevant experiences for US policy makers. Studies on HIEs in other countries were included as long as they were published in peer-reviewed journals.

Building off of the previously noted working definitions and other limitations, the key exclusion criteria were:

A. Studies examining HIEs strictly for health care use and/or health care quality limited only to a single setting, individual or patient level, e.g., specialty consults and chart reviews

B. Studies using HIEs only as a data source, e.g., for general clinical research or other patient care related research, etc.

C. Studies limited to using HIE for other types of public health reporting, e.g., biosurveillance, notifiable diseases, laboratory reporting, etc.

D. Studies limited to general HIE implementation experience, e.g., startup, perceptions, financing, organizing, sustainability, etc.

Simply put, if a review of the article title or abstract indicated HIEs purely from a health care delivery oriented perspective with no connection to population health or public health, these were excluded without further review. A summary of the inclusion and exclusion criteria is listed in Table 2.
### Table 2: Inclusion/Exclusion Criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Published in English</td>
<td>Examining HIEs strictly for health care use and/or health care quality limited to a single setting</td>
</tr>
<tr>
<td>Population health perspective, aggregate data level <em>not</em> limited to individual or patient specific</td>
<td>Reviewing public health IT applications/functionality are not already an included capability within an HIE such as consults</td>
</tr>
<tr>
<td>Peer reviewed for PubMED</td>
<td>Use of HIEs only as a data source e.g. for general clinical research or other patient care related research</td>
</tr>
<tr>
<td></td>
<td>Use of HIE for other types of public health reporting e.g. biosurveillance, notifiable diseases</td>
</tr>
<tr>
<td></td>
<td>Reviews limited to general HIE implementation experience e.g. startup, financing, organizing, challenges, perceptions</td>
</tr>
</tbody>
</table>

**Sources**

While it was expected that there would be limited literature available related to HIE use for population health, the only database used for the initial search was PubMED. This restriction was largely due to extensive previous use for researching similar topics, reliability and quality of available studies, as well as ease and efficiency with which high quality customized searches and drilling can be performed.

Given the very limited number of relevant scholarly articles found through PubMED, other sources were then included. Other databases used were CINAHL and Embase. Other pertinent studies if relevant were reviewed by scanning article references if not found in one of these databases.

In addition to these databases, government websites were considered, using the same search criteria and specifically looking for reports or case studies—not simply recommendations or policy pieces. Government sites included HHS healthit.hhs.gov and CDC www.cdc.gov. In addition, three non-governmental organization websites were also considered using the same

Search strategy

The search terms were drawn from the research question and working definitions. The keywords were all initially tried in various combinations on search databases and websites. The emphasis was to keep the search as broad as possible given the limited results that were anticipated. In fact, in a quick query in PubMed on August 9, 2014 on the term, “health information exchange” only 440 results were returned as compared to 7962 results for a query on “electronic health records”. The general concepts and search term combinations used are listed in Table 3.

Table 3: Summary of Search Strategy

<table>
<thead>
<tr>
<th>Concept</th>
<th>Search terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health information exchange</td>
<td>Health information exchange</td>
</tr>
<tr>
<td>Population health</td>
<td>AND Public health OR population health OR population level</td>
</tr>
<tr>
<td>Primary care</td>
<td>Quality OR measures OR metrics OR indicators OR surveillance</td>
</tr>
<tr>
<td>Surveillance</td>
<td>Primary care OR prevention</td>
</tr>
<tr>
<td>Quality</td>
<td></td>
</tr>
<tr>
<td>Measures/Indicators</td>
<td></td>
</tr>
<tr>
<td>Capacity/Readiness</td>
<td></td>
</tr>
</tbody>
</table>
Titles and abstracts were reviewed in first pass to assess fit with inclusion criteria along with articles that were duplicated in successive searches were excluded. Remaining potential studies for inclusion were read in detail with respect to inclusion/exclusion criteria. No other subjective quality ranking or assessment was done of qualified studies beyond the baseline inclusion/exclusion criteria. Given the anticipated lack of scholarly literature, it was deemed unnecessary within the scope of capturing anything possible in light of the already narrow inclusion/exclusion criteria.

Results

The PubMed search yielded 109 articles, CINAHL produced 43 articles, and Embase yielded 198 articles, last updated on July 26, 2012. But scans of the 5 government and non-governmental websites produced no usable reports for analysis. Through a review of titles and abstracts against the inclusion/exclusion criteria (See Table 2) the number of captured articles was reduced to 6 articles. Subsequent full article reviews resulted in a final set of 4 which served as the basis for this analysis. A thorough review of the references for each of these 4 articles was performed including abstract reviews but no additional articles were added to the final sample. Many of the references for these articles are grey in nature and other cited scholarly literature did not relate to or address the topic of this literature review.

There was very limited available literature, and there were no clear themes amongst the scant papers, rather two loose groupings. Three papers essentially provided, “thought perspectives” and the other paper provided, “implementation perspectives” based on experiences from an HIE deployment for population health. While no usable reports were pulled from the website searches, a multitude of grey literature such as proceedings, policy recommendations, commentaries, etc. were all consistent in echoing the sentiments of the studies that were included
in this review, the potential benefits of HIE/health IT for population health. A summary of study themes is listed in Table 4.

**Table 4: Article Themes**

<table>
<thead>
<tr>
<th>Thought perspectives</th>
<th>Implementation perspectives</th>
</tr>
</thead>
</table>

**Thought Perspectives**

Similar to the common themes found in much of the grey literature, these papers described overarching concepts and potentials for meaningful and usable constructs for HIEs and other health information technology for population health. In essence these articles provided a broad snapshot of possibilities for HIE use in various public health functions of which population level management is one aspect.

Shapiro (2007), provides a basic outline of several potential use cases of the technology for public health. He highlights the driver for population-level quality monitoring use case. That is, the growing epidemic of chronic diseases and the increasingly active role played by public health in prevention efforts. While the quality of preventive-care efforts is recognized as being poor, the inability to perform cross-community level monitoring of providers and payers has confounded matters. The expectation is that HIE offers a potential opportunity to cut across
traditional institutional silos of various community health care stakeholders and provide public health an enhanced capability to monitor quality metrics at the community level.

To evaluate such an HIE use case, a pre- and post-implementation study is suggested. Central to this, would be the use of a standard set of quality measures, which select from the range of sets developed by several organizations (i.e. NCQA HEDIS, CMS Quality Measures). Also, these measures must be evaluated for each HIE implementation and for the target diseases that a local health department wants to monitor.

In addition, Shapiro (2007), notes that early phases of HIE development will likely center around efficiency measures (decreased duplicate tests, decreased LOS, etc.) and costs (monetization of safety/quality measures noted). Ultimately, as these HIEs spread and are interoperable the nationwide health information network (NwHIN) will coalesce, and quality and safety effects will then accrue and become measurable. This coalescing, takes the organizational form of health information organizations (HIOs) as Shapiro et al (2011) describes.

Unfortunately, Shapiro et al (2011) note the primary use case for most HIOs is “centered around direct patient care with the primary goals of improving providers’ access to information…” However, the HIOs do provide the overall organization, infrastructure, technical expertise, and other aspect to enable the HIE for each of the stakeholders. Furthermore, public health can still leverage the HIE to promote several public health use cases. Through local HIE engagement, public health can have its requirements incorporated assuming the required data is available in electronic form, public health analytics are created, and importantly the HIOs recognize the value of public health use cases. This recognition has been helped by national recognition by HHS’s Office of the National Coordinator (ONC) which in its main health IT
goals has specifically called for the improvement of population health, which in effect recognizes the public health use cases as part of HIE development.

There are very few implementations of these ideas and scant evidence in the literature on the various use cases describing improvements in public health using HIE. Building on Shapiro (2007) a description of 11 potential use cases where HIE can potentially improve public health has been outlined (Shapiro et al., 2011):

1. Mandated reporting of laboratory diagnoses
2. Non-mandated reporting of laboratory data
3. Mandated reporting of physician based diagnoses
4. Mass casualty events
5. Disaster medical response
6. Clinical care in public health clinics
7. Public health alerting: patient level
8. Public health investigation
9. Non-mandatory reporting of clinical data
10. Public health alerting: population level
11. Population level quality monitoring

The Shapiro et al (2011) paper brings in several biosurveillance related use cases. However, for this review the population level quality monitoring use case was of primary interest. Similar to the HIE evaluation paper, the growth of chronic disease prevalence is cited as a key motivator for pursuing use as a means for improving public health HIE. This motivator is further augmented by highlighting the inadequate current methods for quality of care measurement.
Notably, manual and costly chart reviews or claims based analysis of only insured patients, all of which occurs largely within the confines of closed systems, with neither approach supporting ongoing population level quality monitoring. Public health could potentially leverage HIO infrastructure not only to harness required data elements, but also to link patients across institutions if needed or simply generate summary quality measures for individual institutions.

Benefits aside, Shapiro et al (2011) also note significant concerns about the financial viability of HIOs and notable failures, particularly evolving business models for sustainability. Nonetheless, there were over 190 HIE projects underway in 48 states from a 2009 survey. While clinical use is the initial motivation for most HIOs, Shapiro et al (2011) advocate for public health’s early involvement in the inception of local HIEs. A variety of technological methods to support the different public health use cases may often be required and public health input is necessary to obtain the benefits from these use cases. In light of the recent unprecedented national investment in health IT, a wealth of new electronic data available is on the horizon. As such, the new HIE infrastructure must also be required to demonstrate the ability to support these public health use cases. Sharing this message, Nangle et al (2009) echo the sentiments and highlight the potential benefits of HIE to various aspects of public health mission and practice.

Nangle et al (2009) have categorized their HIE applications for public health into the “Five P’s” of public health:

1. Protecting citizens from harm due to natural or manmade disasters
2. Preventing unnecessary injury, illness and death through health education
3. Promoting healthy lifestyles and offering information that encourages healthy choices
4. Providing basic primary and preventive health services to disadvantaged and vulnerable populations
5. Participating in healthcare reform

Similar to Shapiro et al (2011), Nangle et al (2009) note the initial goals of HIE are to improve patient care but public health organizations need to identify areas where HIE can be used to improve the public’s health. Nangle et al then provide an informatics perspective on each P and the priority for participating in the HIE for each P.

The Ps of most relevance for this review are Preventing and Promoting and below is a brief summary of the areas. “Preventing,” population level activities are targeted but note that historically prevention measures have been especially effective for maternal, infant, and child health. Subsequently, today there are numerous public health informatics applications dedicated to child and maternal health i.e. newborn screen, heel stick, etc. Beyond child and maternal health, disease registries are highlighted as ripe for HIE inclusion and would provide new venues to connect private providers to public health-managed, population-based clinical information systems.

“Promoting,” programs seek interventions with quantifiable prevention effectiveness and public health informatics has provided critical support for evaluation. Critical to the evaluation has been the development and dissemination of standard indicators for chronic diseases, environmental health, and others. The personal health record (PHR) is highlighted as a possible new communication channel for targeting subpopulations for health promotion activities.

Given the large national investment in EHR/HIE, Nangle et al (2009) note, “the most effective public health leaders and partners in HIE will likely be those agencies that stick to the essential core areas of public health, the “Five P’s”…” Similar to Shapiro et al (2011), they recommend public health’s active engagement in HIE development and go a step further by
calling for state public health agencies to be accountable for using HIE to enhance public health infrastructure to better the mission areas and to improve population health.

Implementation Perspectives

Moving from thoughts and ideas about the potential applications for HIE, Lobach et al (2007) highlight the practical experience in development of an HIE specifically for the improved management of population and care coordination in a North Carolina community. The Northern Piedmont Community Care Network (NPCCN) is an established Medicaid care management program which brings together five counties, 32 private practices, three federally qualified health centers, four community hospitals, nine government agencies, one academic medical center and two care management teams. Lobach et al (2007) developed an HIE for this group using what was originally a limited care management documentation tool and over seven years converted it into an HIE with full communications and collaboration tools for all team members. Information in the HIE includes:

1. Administrative (demographics and identifiers, services used)
2. Care management (care management encounters, health risk)
3. Clinical (encounters, problem/procures, medications, allergies, lab results)
4. Communication (messages and alerts, referrals, notices)

One of the key achievements and biggest hurdles overcome by Lobach et al (2007) was in the creation of a patient matching system for information from multiple sites for a single patient and allow linking of various patient information e.g. lab results, hospital visits, etc. To provide actual population health management, a clinical decision support tool was also implemented to identify care issues and alert care managers as well as care reminder letters to patients. These alerts are
driven off sentinel health events that have been defined and prioritized by NPCCN partners, where care management could potentially provide benefits. Sentinel events and target groups are listed in Table 5 below:

**Table 5: NPCCN’s sentinel events and target groups**

<table>
<thead>
<tr>
<th>Category</th>
<th>Target group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td></td>
</tr>
<tr>
<td>Hospitalization by patient w/asthma</td>
<td>Pts w/asthma</td>
</tr>
<tr>
<td>Hospitalization by patient w/diabetes</td>
<td>Pts w/diabetes</td>
</tr>
<tr>
<td>ED Encounters</td>
<td></td>
</tr>
<tr>
<td>ED visit by patient w/asthma</td>
<td>Pts w/asthma</td>
</tr>
<tr>
<td>ED visit by patient w/diabetes</td>
<td>Pts w/diabetes</td>
</tr>
<tr>
<td>3+ ED in 90 days</td>
<td>All</td>
</tr>
<tr>
<td>Low severity ED</td>
<td>All</td>
</tr>
<tr>
<td>ED for fever</td>
<td>Aged 0 to 20</td>
</tr>
<tr>
<td>ED for pregnancy related reason</td>
<td>Women</td>
</tr>
<tr>
<td>Coordination</td>
<td></td>
</tr>
<tr>
<td>2+ missed appts. In 60 days</td>
<td>All</td>
</tr>
<tr>
<td>Childbirth, need for post-partum follow up in 6-8 weeks</td>
<td>Women</td>
</tr>
</tbody>
</table>

The HIE and associated sentinel event algorithm found that patients in the 19 to 64 age group were much more likely receive an alert and have a sentinel event. The same group was also 2 to 5 times more likely to have a sentinel event. It was also noted that Hispanics were approximately 40% less likely to have a sentinel health events.

Through their HIE, Lobach et al (2007) detected over 7000 sentinel events on over 2000 unique patients across the of 5 communities and demonstrated the ability of an HIE to detect important needs of a population. Key lessons learned include:
• Resolving political issues related to exchange of clinical information and identifying resources to implement the data exchange are often more challenging than technical aspects

• Once system exchange information was online for proactive care management—clinical sites became more open to sharing their information to reap the benefits

• Components of knowledge could be reused e.g. rule for determining if a patient has diabetes was useful for both notices for hospitalization and ED utilization

• Notices of sentinel events had greatest value if they were sent out within a very short time of the actual event

• It is often difficult to determine who a patient’s provider is due to regular changes, making it unclear to whom to send the alerts

Notably, Lobach et al (2007) were able to provide this enhanced population health management through an HIE largely functioning off of billing/claims data as opposed to clinical data from an EHR and note, “this approach is a minimalist view of what could be possible in terms of population health management if a more comprehensive clinical data set were available.”

Discussion

The paucity of evidence suggests that using HIEs for public health chronic disease surveillance is still in its infancy. The evidence captured in both Shapiro papers (2007 & 2011) and the Nangle (2009) papers presented HIE for population health measures as a much needed and powerful application, but acknowledged the lack of research in this area. Both papers by Shapiro (2007 & 2011) on HIE evaluation and uses for public health made it clear that using the
capabilities for population level quality reporting would be an important and much needed function as no ability for cross-community monitoring currently exists. Shapiro (2007) does recognize that the nascent nature of HIE itself and the still evolving technology and processes have limited what HIE could be, “…often because a functional HIE network is not yet available.” Shapiro (2007) recognizes that initial evaluation on HIE will target efficiency measures, such as decreases in duplicate lab tests, decreases in LOS, etc. Demonstration of these initial benefits may support and fund further development of an HIE which can bring increasing benefits to public health. Almost 3 years later, Shapiro et al (2011) in the HIE for public health reported that progress has been made but is still quite a ways away from having HIEs maximizing the public health use potential.

To their credit Nangle et al (2007) do provide some examples of HIE projects that have incorporated aspects of the potential benefits of HIE for public health, that Shapiro et al (2011) note. Unfortunately, the applications are of limited scope; while meaningful they do not provide a significant evidence base for the many potential benefits that are being touted for public health. Nonetheless, Nangle et al (2007) do provide an interesting context for public health’s engagement with HIE, in the form of national health care reform. Specifically, pressing for public health to push for the development of interoperability between the public health information infrastructure and the health care industry. Thereby, public health serving as the catalyst and fulcrum for standardized clinical data exchange among providers to complete the community care continuum, reduce costs, and improve quality.

Building on these ideas with a built from the ground up application, Lobach et al (2007) provide a small scale proof of concept for the potential shape and form population based health management can take with an HIE. While both of the Shapiro (2007 & 2011) papers and Nangle
et al (2009) presented feasible concepts, Lobach et al (2007) translated these concepts into practice on a small scale. The study was limited to a Medicaid population across five counties rather than entire communities but the HIE does include the data on nearly 90,000 unique patients as opposed to the smaller subset of approximately 12,000 Medicaid patients.

Lobach et al (2007) were able to detect and track sentinel events for these patients that would require necessary follow-up with prevention and primary care activities. Whereby potentially, the patient benefits with better more proactive care but the health system benefits with lowering costs and reducing expensive ED visits, hospitalizations, missed appointments, and others. Importantly, Lobach et al (2007) demonstrated HIE mediation of captured data points (billing/claims data in this case) and rapid aggregation, analysis, and alerts based on population health level visualization.

The reviewed literature aligns with the broader consensus in the grey literature as well. A generally held belief and position taken by leading authorities in the field that HIE based population health tracking and measurement is essential for achieving “meaningful use” of health IT. Now, fueled by legislation that provides over $35 billion for health care to adopt these technologies (HITECH Answers, 2014), the “Health Information Technology for Economic and Clinical Health Act” (HITECH) provisions within the American Recovery and Reinvestment Act of 2009 (ARRA) calls for nation-wide provider adoption of interoperable health information technology, and has augmented adoption numbers. ARRA provides financial incentives through the Medicaid and Medicare programs encouraging eligible hospitals and clinical professionals to adopt certified EHR and health information technology coupled with HIE to demonstrate use in a meaningful way. Critically, “meaningful use” sets specific objectives, including those for
population health, specifically for providers to submit electronic health indicators and for local public health agencies to be able to receive them.

HHS’s “meaningful use” criteria, being developed in three stages over the next 4 years calls for provider’s health IT including certified EHRs to meet specific objectives in order to receive incentive payments. Stage 1 criterion which have been completed and incorporated initial public health requirements (HealthIT.gov, 2013):

- Capability to submit electronic data to immunization registries or immunization information systems and actual submission according to applicable law and practice.
- Capability to submit electronic data on reportable (as required by State or local law) lab results to public health agencies and actual submission according to applicable law and practice.
- Capability to submit electronic syndromic surveillance data to public health agencies and actual submission according to applicable law and practice.

Moreover, Stage 3 criteria set for development in 2015 will explicitly call for health IT specifications to improve population health. The criteria for Stage 3 are under public comment at the moment but by and large many of the prior Stage 1 and 2 criteria are being enhanced to incorporate higher thresholds for providers to meet minimum “meaningful use”. In addition, new features to include “one button” transmission of notifiable diseases to public health agencies as well as the option for the patient generated data to be transmitted directly are being considered (Public Health Reporting Initiative, n.d.). Nevertheless, while promising, wide-scale provider adoption of EHRs and HIE capable of fully complying with “meaningful use” criteria is still
many years off (Charles et al., 2012; Hsiao et al., 2011). The upshot being a window of
opportunity for public health to engage in the national discourse on population health
specifications for health IT, especially for chronic disease surveillance which has not received
similar attention. Notably, the studies reviewed here provide the beginnings of an evidence base
for realization of the final Stage and ultimate goal of health IT from patient to population.

Limitations of the Literature

This review may not have been exhaustive compared to a systematic review.
Furthermore, public health informatics, and more importantly population health informatics, is a
relatively new topic in the profession. This novelty may limit the ability to compare findings
with other similar research, especially since there were so few found in the scholarly literature.
Lastly, the topic newness may have also confounded the search itself. It is quite possible that a
portion of relevant literature may not have been captured due to variation in definitional
interpretation resulting in a semantic web that could not capture every shade of meaning for
terms used in studies.

Even with the few studies that were part of this review, it was clear that common
terminology such as public health, population health, measures, indicators, quality, etc., were
being used in largely generic and interchangeable forms. While the authors themselves may
know precisely to what they are referring, it was not as obvious from the texts. Therefore,
“inferential leaps” had to be made using not only the context provided in the study but also
personal experience, expertise, as well as trends from the grey literature. What can be taken
away, however, are general impressions that can be adapted and focused to better define and
articulate key operational metrics necessary for maximizing population health utility in HIEs.
Further, no formal quality assessment was performed on the final selection of literature. This choice was motivated by several reasons. Given the nascent nature of HIEs and the use of these technologies for population health, precise criteria or even simple concept of operation is largely undefined. While there is general consensus as evidenced by the plethora of grey literature advocating the development, use, and diffusion of population health functionalities into emerging HIEs, the policy, process, and technology remain largely amorphous. As such, it was unnecessary to apply common quality criteria to subject matter that is still being defined. As was the case, there were limited details on specifics such as indicators, measures, data sources, data linkages, process descriptions, stakeholder descriptions, etc. making it all the more clear a need for more rigorous evaluation of HIE for population level health management.

Also, and as is the case with many applications of health IT, they are typically not generalizable. The value of these studies is not in the specific conceptual or technological approaches used, rather the overarching takeaways which apply more broadly to the process of setting, translating, and achieving business defined goals, in this case population health, into reality. Therefore, the takeaways from these studies serve to provide highlights of the possibilities but applicability to broader contexts is still on a case by case basis as there is an insufficient evidence base.

**Gaps and Implications for Research**

Against the back drop of national transformation in “wiring” health care with a larger focus on individual patient care delivery, the review was an important opportunity to explore what literature is available and how or what has been done relative to potential use of these new technologies for public health. In addition, it highlighted a need for clarity in navigating the subtle and obvious differences in outlining research as it relates to definitions for: population
health, public health, health care, health quality measurement, and population health status. To be clear, HIEs are for all current purposes used for a patient population. A patient population is a subset of the general population which may or may not have had any interaction with the local health providers and systems. Subsequently, the context of population health has to be clearly defined whether patients or broader general population are being referred to.

It is understood that HIEs will not eliminate the need for other more common population health data sources such as administrative databases, surveys, and other common sources held by various private, local, state, and federal authorities. However, this understanding begs the question, that in an ideal state of 100% EHR and HIE penetration for any given community’s providers, what percentage of the general population are captured as patients within the HIE? Although no community level HIE was used rather point to point provider EHR based HIE to public health, the Department of Health in New York City has shown, the proportion of patients within the general population is very high—with 2600 providers of the almost 9000 (almost 30%) in New York City using the Department’s EHR, the Department of Health has captured nearly 2.5 million patients of the roughly 8.4 million general population of the city, correlating to almost 30% of the general population (De Leon & Shih, 2011). Naturally, the type and amount of data captured for each individual, relevance, quality, and usability to population health, data linking and aggregation (just to name a few issues) would have to be clarified; but the power and implications of the HIE, as a future foundation and community hub for information- if built appropriately-for population health is enormous.

Building on this foundation, is the intrinsic capability for shared EHRs via HIE to provide real-time decision support, cross community care coordination, and feedback loop systems for clinicians and public health practitioners alike. Gone would be the days of disjointed,
disconnected, and bygone reports that often take 6 to 9 months to produce on chronic disease and health statuses which are not timely enough to allow for proactive population health management. What is now regarded as clinical data could be transformed into statistical data at population levels. For example, data that are being collected solely for clinical patient management purposes would also have a high yield for population health monitoring and health care performance measurement. Collection of data at the point of care for patient management improves data quality and completeness, in contrast to data requested or required only for secondary purposes seemingly unrelated or only indirectly related to patient management.

The degree to which existing health information systems can facilitate data collection is, however, constrained by limitations such as the prevalence of data recorded as unstructured narrative or text, lack of standardization for data content, and data access issues due to silos created by legacy systems and organizational boundaries. As such, there are still numerous issues that need to be addressed including, data quality and completeness, use of unique patient identifiers, privacy, lack of and consistent implementation of standards, and large volume of data analysis, available skilled public health informaticists, amongst many others. If health information infrastructures and underlying health information systems are to be adapted for population health however it may be defined, any one of these areas offers rich opportunities for deeper research.
CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

Evaluation Framework

As the national landscape evolves to an electronic health information infrastructure, the nature and direction of HIE projects will evolve as well (Dullabh et al., 2011; Rosenfeld et al., 2006). Local HIE projects not only provide a glimpse into the national transition but represent an incremental learning process that can inform both state and national development. However, as evidenced by the literature review, there is very limited scholarly research on public health functions and the use of HIE, and even less on surveillance of chronic diseases, especially as it relates to capacity and readiness. Therefore, to help structure and guide this evaluation, the CDC’s “Updated Guidelines for Evaluating Public Health Surveillance Systems” (2001) was adapted to provide the overall approach for this study. Based on the CDC’s “Framework for Program Evaluation in Public Health,” the guide provides a comprehensive, step-by-step process for guiding the evaluation of public health surveillance systems. Simply put, it serves as a “how-to” guide for surveillance systems evaluations. The guide is broken down into six major sections:

1. Engage the Stakeholders in the Evaluation: These are stakeholders who will provide input into the evaluation to ensure relevant questions are answered by the surveillance system, and may subsequently be key consumers of the surveillance system outputs. Stakeholders may include public health practitioners; health care providers; data exchange providers; local/state/federal government and others.
2. **Describe the Surveillance System to be Evaluated**: This section is made up of three sub-sections, description of the importance of the health related event under surveillance; description of the purpose and operation of the surveillance system; and description of resources used to operate the surveillance system.

   a. The first sub-section outlines an approach to characterizing the importance of the health event under surveillance and provides some sample indicators such as frequency of cases, severity, disparity, costs, and others to support the case for surveillance.

   b. The second sub-section makes explicit the operation of the surveillance system including health events being monitored, where the system resides, legal authority, and system components.

   c. The third and final sub-section focuses on the requisite resources to operate the system with funding, personnel, and any other required resources that should be assessed.

3. **Focus the Evaluation Design**: This section emphasizes the need for clarity and well defined purpose, questions, and outputs from the evaluation.

4. **Gather Credible Evidence Regarding the Performance of the Surveillance System**: This section provides a list of key metrics to evaluate system performance and includes elements such as usefulness, simplicity, flexibility, data quality, acceptability, and others.

5. **Justify and State Conclusions, and Make Recommendations**: The final recommendations should link back from performance metrics/standards to identified stakeholders and
whether the system is addressing an important public health issue and is meeting the objectives.

6. **Ensure Use of Evaluation Findings and Share Lessons Learned**: A thoughtful strategy for communicating and translating the results of evaluation should be tailored to meet stakeholder needs so as to avoid missing lessons learned and enabling decision making to move recommendations forward.

The flow chart on the following page (Figure 1) depicts a simplified view of a generic disease surveillance system:
In using the CDC’s guide, it is understood that the HINSTX, and indeed most HIEs, are not public health surveillance systems in and of themselves rather they are the potential information conduits (as depicted by the arrows in figure 1) that enable the electronic
transmission of relevant clinical and administrative data between partners. For the purposes of this research, the interconnections enabled by the HIE and the characteristics and capacity of the local jurisdictions to leverage this capacity for chronic disease surveillance functions were explored.

The unit of analysis was the local public health agency, one of the key functions of which is to carry out public health surveillance activities. Furthermore, this study was done before HINSTX has become fully operational, and it was to evaluate the current capacity of LHDs to potentially use the new HINSTX data streams for chronic disease tracking and monitoring, and therefore, was not an assessment of an active surveillance system. Subsequently, the CDC’s surveillance evaluation guide was used only as a high level guide to ensure all relevant categories essential to operating an effective surveillance system were covered, as opposed to a strict adherence to all elements of the evaluation guide. For example, parts two sub-section two, and four of the CDC guide are sections that were not directly usable since metrics such as usefulness, simplicity, flexibility, and data quality, could not be assessed; therefore, prospective capacity or readiness assessment metrics to further augment the surveillance evaluation were used.

Time and resource limitations did not allow for primary data collection for each aspect of the CDC toolkit’s sections. As such, data collection and analysis were guided by two criteria 1) utility in public health surveillance practice and 2) importance to HINSTX’s ability to connect and support local public health departments to effectively use HIE for surveillance. Fortunately, the South Texas HIE has already been formed and has already gone through the bulk of the HIE formative steps that are relevant in the first three sections of the CDC’s toolkit and therefore sufficiently addressed most sub-parts. In addition, a longitudinal study to evaluate HIE impacts
downstream on organization evolution and community impacts was beyond the scope of this study.

**Research Design**

To evaluate LHD’s readiness for using HIE for chronic disease tracking and monitoring, the study used a nonexperimental, descriptive approach to review eleven LHDs in the HINSTX service area. In addition, given the nascent nature of HIEs and the limited number of existing studies, a qualitative approach was most appropriate for this evaluation. As noted by Ash and Guappone, since HIE initiatives are immature, formative evaluations using qualitative methods are especially useful because they take into account context and provide rapid feedback to assist with the HIE development effort (Ash & Guappone, 2007). Creswell has further suggested that qualitative design should be selected if a concept needs to be understood (Creswell, 2012).

The research design used a two-prong approach that combined (1) a survey of LHDs in the HINSTX service area to document current capacities for surveillance and (2) key informant interviews of LHD, state, and national officials were used to supplement and provide context for survey data. An overview of the research design is presented in Table 6.
Table 6: Research Design

<table>
<thead>
<tr>
<th>Research Aim</th>
<th>Data Source</th>
<th>Analytical Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>To understand the gaps in current surveillance capacity to manage the potential new data streams including available staffing, processes, IT support, and others.</td>
<td>Capacity survey</td>
<td>Descriptive documentation of LHDs with varying capacity across the service region</td>
</tr>
<tr>
<td>Identify the barriers and facilitators to closing the gaps in community level chronic disease monitoring and tracking capacity.</td>
<td>Key informant interviews</td>
<td>Open coding</td>
</tr>
<tr>
<td>Develop strategies to help guide filling local health department’s surveillance capacity gaps.</td>
<td>Capacity survey</td>
<td>Synthesis of capacity descriptions with themes and interpretation</td>
</tr>
<tr>
<td></td>
<td>Key informant interviews</td>
<td></td>
</tr>
</tbody>
</table>

This study aimed to examine eleven local health departments that make up the service area for HINSTX with respect to organizational surveillance capacity in three domains: people, process, and technology. Development of the LHD surveillance capacity assessment metrics were adapted from CDC’s National Public Health Performance Standards Program (NPHPSP), “Local Public Health System Performance Assessment Instrument” and Hessler et al’s (2009) survey on the relationship between health information exchanges and public health agencies, both of which provide extensive categories of questions relevant for both overall public health functions and those specific to public health information systems. The NPHPSP assessment instrument is a nationally accepted survey tool based on the framework of the ten Essential Public Health Services. The questions are structured accordingly for each of the ten essential services:

1. Monitor health status to identify community health problems.

2. Diagnose and investigate health problems and health hazards in the community.
3. Inform, educate, and empower people about health issues.

4. Mobilize community partnerships to identify and solve health problems.

5. Develop policies and plans that support individual and community health efforts.

6. Enforce laws and regulations that protect health and ensure safety.

7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable.

8. Assure a competent public and personal health care workforce.

9. Evaluate effectiveness, accessibility and quality of personal and population-based health services.

10. Research for new insights and innovative solutions to health problems.

Questions were drawn and adapted from sections one and two of the survey. Survey questions were selected to elicit information across the well accepted model of information systems of people, processes, and technology which was used to frame and organize the key areas of LHD capacity in regards to utilizing HIE for chronic disease surveillance. This model helped highlight the obvious aspects of technology considerations, but also brings into focus people and organizational processes which are often overlooked but essential components that must be addressed to make complex information systems implementations more successful. The survey is included in Appendix 1.
To supplement LHD survey data and provide context, interviews with survey respondent local health directors were done to ensure key themes were captured as well as to build a complete LHD profile. The interview protocol for health directors is included in Appendix 2. Agencies were selected based on the key inclusion criteria of whether the agency performed disease surveillance activities. We found that only the Nueces County LHD, Region 11 health department and Region 8 health department performed disease surveillance functions with the remaining LHDs in the HINSTX service area not performing disease surveillance and were therefore excluded from the study. However, given the regional similarity in the HINSTX service area and that the Region 11 health department supports ten of the eleven LHDs in the HINSTX service area, the Nueces LHD and Region 11 health departments were selected for interview and represented a mix of agencies with one LHD and one region office providing insights into a low resource area with limited surveillance capacity with respect to people, process, and technology.

The study of HINSTX used the LHDs as the unit of analysis and utilized LHD surveys and LHD, state and national key informant interviews focusing on:

1. Understanding the LHD gaps in current surveillance capacity to manage the potential new data streams including available staffing, processes, IT support, and others. The purpose was to generate a baseline depiction of capacity at the LHD level across the HINSTX service area in the form of capacity profiles outlining readiness differences at LHDs in terms of people, process, and technology.

2. Identification of the barriers and facilitators to closing the gaps in community level chronic disease monitoring and tracking capacity. The identification of these barriers and facilitators helped to provide an understanding and description of the underlying cause(s)
for the potential gaps in readiness, as well as enablers and interest of LHDs for leveraging HIE for chronic disease surveillance and the types of support services, collaborations, and technical infrastructure that LHDs perceive to be helpful for effectively utilizing HIE for public health functions.

There are some limitations related to the data sources used. The sample size was significantly limited because, there is only one full-service LHD in the HINSTX service area, Nueces County Health Department that performs surveillance functions and met the criteria for inclusion, with all other counties largely being covered by the Region 11 health department (see Table 7). However, Directors from both Nueces LHD and the Region 11 health department were asked to recommend additional staff, whose roles involve interactions with other counties in the region and who would be amenable to being interviewed, in order to provide insights into counties not included in the study. In addition, to further augment and gain additional perspectives on local findings, state and national level health officials were interviewed to reflect on challenges and opportunities with HIE for public health use.

Further, the data collected through the survey relied largely on the appropriate individuals completing it and having the necessary information, time, knowledge, and expertise to ensure it is answered accurately and truly reflects current capacity. In addition, given the evolving state of the HIE landscape and varying levels of public health engagement there may be systematic differences in respondent knowledge and information across jurisdictions and over time. Finally, while the survey was carefully developed there may be some variation in how respondents interpret questions due to ambiguity and lack of understanding. To help enhance the reliability of survey data and better frame questions, the survey was pre-tested by a non-surveyed LHD in
Texas to enhance clarity. Additionally, respondents were given contact information in order to provide clarifications as needed.

**ONC Direct Pilot Project**

For this study we selected one of ONC’s Direct Project pilots for the HIE evaluation, HINSTX. The Direct Project was launched in 2010 and is (HHS, 2012):

“…part of the Nationwide Health Information Network, to specify a simple, secure, scalable, standards-based way for participants to send authenticated, encrypted health information directly to known, trusted recipients over the Internet in support of Stage 1 Meaningful Use requirements.

Information transfers supported by Direct Project specifications address core needs, including standardized exchange of laboratory results and transmission of information to public health agencies.”

A key reason for selecting an ONC Direct Project pilot was based on the vetting that these sites have already been through with the ONC application process to confirm commitment, local support by various stakeholders, dedicated funding for the pilot duration, national visibility, and an established feedback structure for providing lessons learned and takeaways from the evaluation to local officials and to national policy makers as well.

**Local Setting**

The configuration of public health services in the state, and the majority of LHDs in the HINSTX service area are not full service public health agencies. The Texas Department of State Health Services (DSHS) is assigned the statutory responsibility to address the health needs of the state and contracts with LHDs to deliver most of its prevention activities. While Texas law authorizes counties and cities to create a public health department within their jurisdiction, they are not obligated or required to do so. To further support and/or provide the full range of public
health services, each county in the state is assigned to one of eleven state designated health service regions as shown in Figure 2 below (Texas Health Institute, 2012).

**Figure 2: Map of Texas Health Service Regions**

Many of the LHDs in the HINSTX service area provide a limited set of services such as food service inspections, immunizations, and environmental assessments; or they provide administrative services (i.e. indigent care and health communication). Those same LHDs do not perform other routine infectious disease or chronic disease surveillance activities or have no local health department established. Notably, all of the LHDs in the HINSTX service region are supported by the health service Region 11 health department with the exception of Karnes County, which is supported by the region 8 health department. Subsequently, only Nueces
County was included in the study for the survey as well as the health service Region 11 health department, which provided the most comprehensive picture of LHD surveillance capacity in the HINSTX service region.

Table 7 below lists the counties in South Texas that will be serviced by HINSTX, population, and classification based on the National Center for Health Statistics (Ingram & Franco, 2012) urban-rural classification system. All eleven counties were reviewed, including contacting LHDs where applicable and contacts with both health service region offices (R8 and R11) to confirm eligibility for inclusion in this study i.e. perform disease surveillance functions.

Table 7 below provides a summary of the eleven LHDs.

Table 7: Summary of HINSTX service area LHD Review (Texas State Historical Association, 2013)

<table>
<thead>
<tr>
<th>County</th>
<th>Population 2012</th>
<th>Area (sq. miles)</th>
<th>Classification/Region</th>
<th>LHD/Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aransas</td>
<td>23,818</td>
<td>528</td>
<td>Medium metro/R11</td>
<td>Yes/Limited</td>
</tr>
<tr>
<td>Bee</td>
<td>32,527</td>
<td>880</td>
<td>Micropolitan/R11</td>
<td>Yes/Limited</td>
</tr>
<tr>
<td>Brooks</td>
<td>7,161</td>
<td>944</td>
<td>Noncore/R11</td>
<td>No/Limited</td>
</tr>
<tr>
<td>Jim Wells</td>
<td>41,754</td>
<td>868</td>
<td>Micropolitan/R11</td>
<td>No/Limited</td>
</tr>
<tr>
<td>Karnes</td>
<td>15,233</td>
<td>754</td>
<td>Noncore/R8</td>
<td>No/Limited</td>
</tr>
<tr>
<td>Kenedy</td>
<td>431</td>
<td>1,946</td>
<td>Micropolitan/R11</td>
<td>No/Limited</td>
</tr>
<tr>
<td>Kleberg</td>
<td>32,025</td>
<td>1,090</td>
<td>Micropolitan/R11</td>
<td>Yes/Limited</td>
</tr>
<tr>
<td>Live Oak</td>
<td>11,664</td>
<td>1,079</td>
<td>Noncore/R11</td>
<td>Yes/Limited</td>
</tr>
<tr>
<td>Nueces</td>
<td>347,691</td>
<td>1,166</td>
<td>Medium metro/R11</td>
<td>Yes/Full Service</td>
</tr>
<tr>
<td>Refugio</td>
<td>7,259</td>
<td>818</td>
<td>Noncore/R11</td>
<td>Yes/Limited</td>
</tr>
<tr>
<td>San Patricio</td>
<td>65,600</td>
<td>708</td>
<td>Medium metro/R11</td>
<td>Yes/Limited</td>
</tr>
</tbody>
</table>
**Data Collection Plan**

Primary data collection was completed in two phases, 1) a survey instrument to collect current LHD surveillance capacity information and 2) semi-structured interviews of key informants to provide the context for LHD surveillance capacity, especially regarding facilitators and barriers in enabling HIE for improving chronic disease surveillance. For the first phase, the survey instrument was designed to capture current LHD surveillance capacity regarding people, processes, and technology necessary to perform the necessary functions. Survey questions are a combination of fixed and open ended responses that allowed for comments. A pre-test of the survey was performed by the local health department in San Antonio, Texas which was not part of the LHD survey group for HINSTX. Pre-test respondents were asked to identify survey items that were ambiguous, not applicable, subjective or otherwise not clearly answerable and help refine key components of people, process, and technology necessary for surveillance readiness.

Based on feedback from the San Antonio LHD no major changes were made to the survey. The survey was administered to one LHD (Nueces) and one Regional health department (R11) within the HINSTX service area via email. The invitation to complete the survey was facilitated by the HINSTX Executive Director which included information on the study purpose, objectives, and instructions for completing the survey. Email and telephone reminders were sent to the LHD and direct encouragement by the HINSTX Executive Director after 3 weeks along with direct survey completion via telephone by the primary investigator with the LHD. There was a 100 percent response rate, which was expected given the small sample size, a combination of intensive follow-up, and the HINSTX Executive Director’s relationship with local health department officials.
For the second phase, health department respondents to the survey were contacted for key informant interviews; to build a complete profile of the LHD to include both basic resources and leadership perspectives. Interviews were conducted with health directors and with other key department technical staff to ensure both high-level management and operational perspectives. Interviews with state and national level officials were conducted after both Nueces and Region eleven interviews were completed. These officials included, one senior official from the Texas DSHS responsible for state HIE efforts, one senior official from a state level health IT advocacy group, and two senior federal officials from the HHS’s Office of the National Coordinator responsible for coordinating national health IT efforts. The Executive Director for HINSTX assisted in identification and recruitment of all local, state, and national key informants and provided additional guidance.

While ensuring our goal of diversity in perspectives both from leadership and operational aspects, we used initial interviews with health department directors, state and national leadership to direct us to programmatic and technical staff in their respective organizations that could provide operational perspectives. Introductory emails and a project overview were sent out in advance to recruited individuals, but questionnaires were not included. All interviews took place by telephone. These were digitally recorded after receiving consent, and each interview took 30 to 45 minutes to complete. At the time of the interviews, as necessary, the interviewer also requested additional interviewee time for follow-up questions which were performed by email. Any documents needed to further support or expand on interviewee responses were also requested.
Data Analysis and Results

The unit of analysis for this research was the LHD. Analysis was performed in two sequential steps. First for Aim 1, the survey data was reviewed to understand LHD resources and capacity along the people, process, and technology dimensions. Second for Aim 2, key informant interview data was summarized by themes. The results of this analysis were then synthesized and interpreted to identify patterns, lessons learned, and to inform recommendations to address Aim 3.

LHD Surveys

Survey responses were compiled in a MAXQDA database, verified and cleansed, and then detailed descriptions generated of current LHD surveillance capacity in regards to people, process, and technology. This analysis was not used to support causal inferences about the effects of more or less LHD capacity in the three domains, but rather was used to describe the pattern of variation in LHD readiness to use HIE for disease surveillance with more or less resources available for people, process, and technology. This descriptive analysis provided a backdrop for health directors’ perceptions about facilitators and barriers for using HIE for chronic disease surveillance and may illustrate some linkages between current LHD surveillance capacity, and perceptions about being ready and able to exploit the capabilities provided by HIE.

Key Informant Interviews

A total of 11 interviews were conducted between February and July 2014 to supplement the surveys and provide additional context for the potential use of HIE for chronic disease surveillance by LHDs using a semi-structured interview guide. Key informants from both the Nueces LHD and Region 11 health department were selected and included three epidemiological staff, two information technology staff, one LHD director, and one region health department
director. In addition, one state health department official engaged in public health HIE, one state health IT advocacy representative, and two national level officials from HHS’s Office of the National Coordinator were included to provide broader context on state and national efforts and polices to advance HIE for public health. As such, interviews with state and national level officials were asked some similar questions to the LHD officials but were generic and not specific to any one locality, HIE, etc. and more reflective on some of the challenges and opportunities that have been posed by earlier local informants.

After the completion of each interview, initial impressions and observations were noted ensuring that all key questions were covered and any additional comments were included in the analysis. No direct interview subject attributions were made, and numbers were assigned to interviewees to further de-identify informants. Generic statements such as, “a key informant”, and other broad labels were used to provide perspectives on individual opinions. The interviews were transcribed using Nuance Software’s Dragon Naturally Speaking. Digital recordings and transcriptions were all secured in password protected files on an encrypted laptop and backed up on password protected cloud based storage using Microsoft’s secure SkyDrive. Issues and themes were then identified and coded using MAXQDA software for qualitative data analysis. The data was then categorized and themes were open coded and tabulated to identify all common threads that emerged from frequent mentions within or across interviews. This process of categorization was iterative and was followed after each cycle of interviews, between 2 and 3 interviews and the categories and themes were refined as more interviews were done and organized into a final summary of themes.

1 SkyDrive is a file hosting service that allows users to upload and sync files to cloud storage and then access them from a Web browser or their local device while allowing users to control access and keep the files private by using a secure login.
CHAPTER 4: RESULTS

Aim 1
To assess the gaps in current surveillance capacity to manage the potential new data streams including available staffing, processes, IT support, and others.

Survey Responses
One LHD and one region health department provided completed surveys. This delineation was based on our finding that only one LHD performed surveillance functions, Nueces and that Region 11 health department was the main public health support office for the majority of the other counties in the HINSTX service area that only provided limited services. Table 8 below describes key characteristics of Nueces County and Region 11 health departments across the people, process, and technology domains.

Table 8: Key People, Process, and Technology Attributes

<table>
<thead>
<tr>
<th>Domain</th>
<th>Nueces County LHD</th>
<th>Region 11 Health Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>People</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Staff (FTE)</td>
<td>4-5</td>
<td>161-165</td>
</tr>
<tr>
<td>Epi/surv staff</td>
<td>1 - Infectious disease coordinator for communicable diseases, 1 IT/HIE specialist</td>
<td>5 Birth Defects, 1 immunizations (vaccine-prevention), 3 zoonoses, 6 epidemiologists</td>
</tr>
<tr>
<td>IT staff</td>
<td>2-3</td>
<td>2</td>
</tr>
<tr>
<td>Masters or Doctoral level</td>
<td>Highly adequate - 2 Masters</td>
<td>Highly adequate – Access to</td>
</tr>
<tr>
<td>Process</td>
<td>epidemiologists and/or statisticians</td>
<td>Master’s level epidemiologist at Region 11; access to State Health Department epidemiologist; access to CDC epidemiologist/statistician in emergency situations</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>--------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Size of Population served</td>
<td>343,281</td>
<td>2.4 million</td>
</tr>
</tbody>
</table>

### Process

<table>
<thead>
<tr>
<th>Maintain and/or contribute to one or more population health registries</th>
<th>Diabetes</th>
<th>Cancer and Birth defects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Operate or participate in surveillance system(s) designed to monitor chronic diseases</td>
<td>No – Active surveillance system only for communicable diseases</td>
<td>Yes – Active surveillance of birth defect; Passive surveillance of cancer</td>
</tr>
<tr>
<td>Population-based survey(s) measured the prevalence of some priority chronic health problem and leading risk factors</td>
<td>Yes – Only risk factors but not disease prevalence</td>
<td>No - Limited assessments in public health systems but no surveys of chronic disease</td>
</tr>
<tr>
<td>Timeliness current surveillance system</td>
<td>Largely dependent on patient population as surveys are completed at time service is rendered</td>
<td>Birth defects data is rapidly collected because of connection with hospitals</td>
</tr>
<tr>
<td>Surveillance results reporting</td>
<td>Reported every other year</td>
<td>Monthly for birth defects; Cancer – almost never</td>
</tr>
<tr>
<td>Compliant with national and/or state HIE guidelines</td>
<td>Yes – both; compliant with Public Health Information Network (PHIN) guidelines and Health Insurance Portability and Accountability Act</td>
<td>Yes – both; compliant with Public Health Information Network (PHIN) guidelines and Health Insurance Portability and Accountability Act</td>
</tr>
</tbody>
</table>

---

2 A system employing staff members to regularly contact heath care providers or the population to seek information about health conditions.
<table>
<thead>
<tr>
<th>Maintain written protocols for chronic diseases program</th>
<th>No – in process of developing protocols with additional funding</th>
<th>No – not performing chronic disease surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timeliness of surveillance data feedback to community</td>
<td>Dependent on disease/information - higher emphasis on diseases with higher severity/probability of mortality: Pertussis = 24-48 Hours; Flu = Biweekly &amp; Monthly Stroke = 6 Months</td>
<td>Typically 3 years for most conditions</td>
</tr>
<tr>
<td>Conduct chronic disease health education and/or health promotion campaigns</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

### Technology

<table>
<thead>
<tr>
<th>Total Annual IT Expenses</th>
<th>Approximately $368,740</th>
<th>Not administered through Region program, administered through State Health Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Broadband Internet access</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Top IT priorities</td>
<td>Technical support, software issue reconciliation, networking, electronic medical record troubleshooting</td>
<td>Maintain servers, assuring connectivity for day to day jobs; databases’ functionality</td>
</tr>
<tr>
<td>Availability of IT equipment &amp; necessary software</td>
<td>Adequate</td>
<td>Adequate</td>
</tr>
<tr>
<td>Currently exchanging electronic data with providers, labs, other partners</td>
<td>Yes – limited exchange with State Health Department for immunization data and some national data with CDC</td>
<td>Yes - Receive data from labs statewide, but not providing any data online, not connected to any HIE’s or any providers; some national</td>
</tr>
<tr>
<td>Standards used for data collection</td>
<td>Yes – Operates local registry that will move to the HIE once operable; use local Microsoft Access database/Microsoft Excel spreadsheets to format data</td>
<td>No - 2 year project, working on effort with State Health Department to ensure legal issues are resolved</td>
</tr>
<tr>
<td>Integrated w/national and/or state surveillance systems</td>
<td>Yes – CDC’s National Electronic Disease Surveillance System (NEDSS); Laboratory Information Management System (LIMS); State Health Department database for immunization records</td>
<td>Yes – CDC’s National Electronic Disease Surveillance System (NEDSS)</td>
</tr>
<tr>
<td>Stage 2 of Meaningful Use guidance status</td>
<td>Immunization information – can report out but can’t receive Electronic lab reporting – can receive Syndromic surveillance data – can receive</td>
<td>Immunization information – no Electronic lab reporting – no Syndromic surveillance data – no</td>
</tr>
<tr>
<td>Data &amp; capabilities HIE for surveillance</td>
<td>Gaining access to hospital records in real time; disease plotting/tracking at the population level</td>
<td>Databases, identifiable registries, real time data – much more important than syndromic surveillance data</td>
</tr>
</tbody>
</table>

**People**

The Region health department serves a larger population (than the LHD) and has more staff including the number of staff with surveillance responsibilities. However, the number of IT staff is comparable.

**Process**
While there are few targeted disease efforts for conditions such as diabetes and cancer, neither of the health departments formally operated a chronic disease surveillance program. Surveillance data reporting time for critical communicable disease was generally good; however, broader community feedback was significantly long as noted by the Region office. In addition, both the Nueces LHD and Region 11 health department were compliant with current general public health information exchange guidelines.

**Technology**

Information technology operations and support were noted as the top IT priorities by both health departments with an adequate amount of available IT equipment. While neither department was engaged in any HIE initiative, both departments are involved in very limited direct information exchange with the state health department along with notifiable disease surveillance information integration with CDC. In addition, Nueces LHD has also made progress in achieving ONC’s Meaningful Use Guidance and can receive lab and syndromic surveillance data from providers but not immunization data yet. Beyond this information, there were either only unique local data collection standards or none at all which are necessary for electronic exchange.

**Aim 2**

Identify the barriers and facilitators to closing the gaps in community level chronic disease monitoring and tracking capacity.

**Themes**

A review and analysis of interview transcripts was performed and open coded. Further analysis categorized codes that were mentioned consistently and discussed in detail during the interviews were characterized as key themes. Three key themes emerged to suggest factors that
may accelerate filling the immediate gap in community level capacity for chronic disease monitoring and tracking. Although the key informants represented varying operational perspectives from the local, state, and national levels, there was consistency in the ideas expressed by all to identify the three key themes. Table 9 provides a summary of these themes and descriptors.

**Table 9: Themes from Informant Interviews**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Descriptors</th>
</tr>
</thead>
</table>
| Sufficient trained staff skilled in analyzing the large volumes of clinical data that are realized by HIE must be available to make it useful. | • Skills  
  • Training  
  • Collaboration  
  • Staff time  
  • Prioritization  
  • Funding |
| There must be clearly articulated laws and regulations to help enable the full and effective use of HIE. | • Regulations  
  • Clarity  
  • Legal |
| An overall health IT strategy must be developed and implemented to coordinate and integrate the priorities, goals, and objectives of various public health information technology initiatives to effectively use HIE. | • Standards  
  • Costs  
  • Interoperability  
  • Sharing |

After appraising the data based on the themes, it was assessed in relation to the research aim: Identify the barriers and facilitators to closing the gaps in community level chronic disease monitoring and tracking capacity. While the themes became apparent, the codes offered more detailed descriptions of the specific barriers and facilitators as described by the key informants. Illustrative comments by key informants, within each theme have been highlighted to address the research question.
**Theme 1: Sufficient trained staff skilled in analyzing the large volumes of clinical data that are realized by HIE must be available to make it useful.**

The lack of available skilled staff was consistently raised by almost all key informants and stood out as the single biggest barrier for LHDs to effectively use HIE. One informant specifically emphasized this lack as the weakest link.

“And the people limitations of even being able to analyze all that data...we’re worst prepared with people."

Another key informant noted the need for technology training, in addition to the staffing, particularly at the local regional health departments.

“Lack of personnel or insufficient personnel sometimes, especially the personnel that are trained in technology.”

Another informant further noted that staff limitations have placed more priority on acute and communicable conditions and limiting availability for chronic disease surveillance. However, there was recognition that chronic diseases need to be addressed.

“So we're just kind of limited to doing the acutely or newly diagnostic...for chronic disease surveillance, I think there is lack of data and time, it keeps us from doing more with it, we don't have enough staff or time, that's just something that's kind of been on the side... I mean you got to focus on stuff that is immediate like outbreaks rather than chronic but nonetheless they're still there and they seem to be increasing in numbers so you know something needs to be done.”

While there may be recognized interest and need for surveillance of chronic disease the practical funding limitations were driven home by a key informant.

“There is interest, the problem being lack of sufficient staff, that’s always a problem. I think health districts overall, health departments across the nation probably know what’s important but it all comes down to ‘do we have enough staff to actually do it, and that comes from funding issues unfortunately - that’s the cold hard truth.”
In follow up interviews with federal officials at the Office of the National Coordinator (ONC), they echoed the LHD challenges and noted some of the federal efforts underway to assist local public health departments and fund the personnel resources.

“There are people that you need on the informatics side to actually do the work to translate between the technical people and the business people to make that happen. At ONC when we had a workforce training program we did to actually include some training programs for public health professionals and there was one of those in Texas with the county and state health departments there. CDC funds several informatics fellowships throughout the course of the year in conjunction with the Association of State and Territorial Health Officials (ASTHO) and National Association of County and City Health Officials (NACCHO) and then there are the non-technical people who get the data and - you know what are they going to do with it - that’s a whole other issue - as you get more data in you have to have more people respond to it and then finally you need the money to actually support all of that. So on the money side one of the things that we’re trying to help public health understand is how they can fit into this new world with health care reform and health IT that’s integral to it and some of the funding opportunities that are actually available for that. So we’re trying to do some education series with health departments around sustainability through funding programs like integrating with state innovation model grants through CMS.”

In addition, leadership and collaboration inclusive of agreed upon public health priorities were cited as examples for building the essential partnerships to overcome the personnel capacity challenges. An informant was very vocal about the need for a cultural change in public health and stressed the need to engage public health administrators.

“You know I think there’s still is not the level of engagement when you think about chronic disease you really have to have your hospitals, your doctors, your public health - you have to have everybody at the table altogether, or you’re not going to make any progress. Austin, Texas is a great example, we have very strong partnerships between our local health department, our local mental health department, our hospital district and our two hospital systems - who are fierce competitors, but they’re collaborating on chronic disease because they have gotten to the point where they understand the need to collaborate around chronic disease. That’s a culture thing and again it’s a leadership bank. And so if community is a community, there has to be some driving force to say for example we’re going to take on obesity, were going to take on asthma, we’re going to take on - that means whatever it is - and then sometimes public health doesn’t even get invited to the table - I hear this a lot from public health and mental health - that
there’s these initiatives going on - but nobody even bothers to talk to us - so it’s sort of incumbent on the other stakeholders to reach out to public health.”

Theme 2: There must be clearly articulated laws and regulations to help enable the full and effective use of HIE.

The lack of clarity around the legality of using HIE for bi-directional patient information sharing was a repeated message noted by several key informants. This obfuscation, in part, stemmed from differing interpretations and applications of state and federal legal requirements, potentially conflicting policies and practices for patient consent, and concern about liability for inappropriate disclosures of health information under current state laws. One key informant outlined the issue and the hesitation by public health administrators in part caused by a recent newborn screening program controversy. The state was ordered to destroy several million blood spot card samples legally collected from newborns but kept without parental consent under a federal lawsuit settlement because there was no clear legal authority for DSHS to keep the blood spots indefinitely for research.

“Yes there is a gray area. And let me tell you what the gray area is, the gray area has two aspects to it: if you follow the blood spot thing and that was a problem that means that our state health department feels very paranoid about sharing data because they got in so much trouble. But here’s the other problem- the statutes around the reporting of public health data talk about a providers obligations to report. Those statutes do not address whether providers can delegate that reporting or how health information exchange might participate in either reporting or reviewing the data. It doesn’t say an HIE can’t but it doesn’t say an HIE can, and so there is ambiguity when I talk to lawyers. They are like “well the law does not allow it”, and I’m like “well the law does not prohibit it”, and there like “well that’s too bad because we have to take a very conservative interpretation because the last time we didn’t, we got in trouble.”
The ambiguity of what LHDs can and can’t do seems to have precluded some forward progress in getting chronic disease surveillance operational. A key informant noted the lack of clarity in the laws and exemplified some of the confusion.

“Some of what I’m hearing are some issues are more like the laws that have been written - maybe the laws allow for health departments to receive communicable diseases - if the laws don’t tell - and I don’t know exactly what the verbiage is - they don’t address may be correctly at this point electronic information to be received and so having to go maybe and change the laws seems like maybe that might be what some of the holdup is that’s the biggest theory - I’m not exactly sure again but that might be kind of what’s keeping us from looking forward at this time.”

Even with the lack of clarity another key informant noted some basic tenets that should be followed upfront by all local HIE efforts that can help clear some legal hurdles while waiting for more comprehensive and clear legislation.

“They have to communicate early and define the parameters around partners within the exchange, find out how that information is going to be collected, and how that information is going to be used. And doing so really alleviates a lot of the anxiety among competing institutions participating in the health information exchange. They have to - especially when you’re talking about certain types of diseases they have to really understand how consent and authorization is going to be handled. And doing that up front really helps address, and doing that at a leadership level within an HIE really helps address one of the longest poles in HIE which is getting legal agreement signed and through the legal departments and through the compliance and privacy officers at these various institutions participating in health information exchange.”

Federal officials at ONC further recognized legal challenges for electronic exchange in public health. ONC has elevated these concerns at the highest levels and is working on initiatives that may in part begin to expand federal regulations and help guide state development of their own legislation.

“Yes, it’s a major issue partially because public health has at its core the data that it uses publicly - in other words it’s meant to take in information about - for contact tracing purposes, to do interventions...Where in medicine laws around
data are completely protected and wrapped protections around it - so the HIPPA process - it’s a very different approach to data and an expectation about use - and there is legal work to do in that space completely. Some of that could potentially be addressed by reframing or reworking HIPPA and the White House has actually taken on that as an initiative to address - they have a White House data and privacy report. It doesn’t quite get to the kinds of things you and I are thinking about data but it begins to open up the conversation about what we really need - we need to rethink HIPPA because it’s not inclusive of all types of data or all uses of data. And they’re thinking about it more from the innovator’s dilemma rather than public health but it is all under the same challenges. So we are involved - my privacy and security office is involved in supporting the White House and that initiative and that’s going to be with Congress - on the other hand it’s part of our interoperability roadmap - we will be working on an alignment across the country about policy including privacy and security and looking at how states have addressed the challenge. It’s actually something that comes up quite a bit in conversation and it turns out even as you know within states there is quite a lot of variability.”

Theme 3: An overall health IT strategy must be developed and implemented to coordinate and integrate the priorities, goals, and operations of various public health information technology initiatives to effectively use HIE.

Key informants almost unanimously pointed out the LHD focus on communicable diseases with limited surveillance coverage of chronic disease and associated processes for the collection and reporting of data. While this focus was not cited as necessarily being an issue in and of itself the lack of underlying processes and supporting infrastructure were noted as a technical capacity limitation in preparation for utilizing HIE. As noted, public health has developed and implemented information technology to enhance specific public health program areas, often in a stove-piped fashion, focusing on specific priority public health functions. Therefore, LHDs were hampered in their ability to electronically capture, analyze, and share information needed for community level chronic disease surveillance. One key informant noted some of the limited efforts,
“I mean we don’t have (chronic disease) surveillance per se I think for these conditions. We do have an annual exercise that is done for public health preparedness, but as part of that exercise we put together a clinic where we give these types of service for people who are diabetic or have heart disease and we have a nutritionist on-site for folks who have obesity problems or any kind of nutritional problems or need nutritional counseling. But in putting that on we do get some information on people who come.”

Several informants also noted the limited focus on chronic disease and the subsequent consequences, especially timeliness.

“Well for communicable diseases I think they’ve been - you know - they’ve done fairly well but for chronic diseases, which are diabetes and obesity, they’ve been fairly poor. So it’s really - just to get the information - and it kind of works in reverse. We get the information two years later from the state, it comes to health district and we share the information with the community, which is in their mind and truly is old information. It doesn’t mean it doesn’t pertain it just seems like it’s outdated to them, which it is. And in some instances it takes five years to get back.”

The limited focus and well established processes for chronic disease surveillance were coupled with often uncoordinated health IT efforts by public health agencies.

“I guess the first of it is, is to set uniform standards so everyone is working together, not each one developing their own rules that they’re going to go by. So a more unified approach. It really ought to be statewide or at least region wide in their approach, instead of this piecemeal, see who can make money off it kind of situation we have now.”

The key informant went on to note that this unified approach is critical with the growth of multiple HIEs and standardization with more coordinated and planned development which potentially could lead to more effective technology investments.

“The funding is going to be an issue, because I know that all the HIEs are just borderline whether or not they’ll be able to continue to operate because of funding. Somewhere there we need to ensure that they can move forward in the most economic way possible in validation and fewer HIEs per se.”
The perils in the lack of coordination and not fully planned health IT investments was further echoed by another key informant.

“Right after 9/11 we had some of our health departments actually purchase syndromic surveillance type software that we were reviewing at that time and we were fortunate that we did not purchase because after they bought it, and it cost a lot of money, they found out that they didn’t have a way of communicating with hospitals. While at the level of the state they could talk back and forth, they didn’t have a way of talking locally to their hospitals. Later the state has since moved over in the last year or two to another program called but I have also heard that that’s not very robust and it’s not something that a lot of the other health departments are doing at this time. So we’re kind of all in a waiting game before we put a lot of money into a software system we want to make sure that we can all talk to each other.”

Beyond the lack of health information systems coordination, another key informant stressed the importance of standards.

“There was a case of pertussis, in a newborn - a positive lab test for pertussis - it came across the HIE, the HIE staff realized that the baby was actually in the NICU, and the NICU had not been told that the baby was positive for pertussis. Because of the HIE infrastructure they were able to get that information to the right people at the hospital. Now the hospital should have known that, and they should’ve caught that but they didn’t, so there’s lots of benefit to be gained from getting this information digital and getting it real-time, building dashboards, and looking at chronic disease patterns. You can’t do any of that until you build a standard system that’s interoperable, that leverages the tool.”

ONC officials in particular noted very active work in the area of standards and interoperability and specifically efforts to integrate public health needs for chronic disease tracking into the broader discussion in light of the limited LHD resources available.

“So what we realized with public health is that there are several initiatives within the standards and interoperability framework that pertain to public health. But public health doesn’t really have the resources to meet their needs as those standards are being developed. So, what we did was develop the Public Health Tiger team which is a cross initiative health forum where we bring together people working in public health - whether they’re state or local health departments, people at CDC, ASTHO and NAACHO and what we’re doing there is trying to document the needs that public health has to integrate with HIEs and
to exchange data. And then we’re aligning those with the various standards and interoperability initiatives. So, we’re working to make sure we understand the local health departments so that we can make sure that that unstructured data capture standards are being developed. When you start asking questions about chronic conditions – and those are certainly some of the issues that have come up on Public Health Tiger team and depending on the issue of problems that we’re trying to solve, I think there are different ways that our Public Health Tiger team are trying to address that. Local public health departments have a real need to know what’s going on. In the 80s with chronic disease and historically they’ve had to rely on survey data and other types of data that are often not timely and are often incomplete. Just as another tool in their tool belt, not to really replace the tools that they already have.”

ONC officials went on to further note challenges even when standards do exist. While standards are a part of the solution, the coordination of multiple technology platforms, vendors and integration was noted as a barrier to effective use of electronic data exchange. Stemming in part from lessons learned from “meaningful use” Stages 1 and 2, ONC officials highlighted a key initiative to help alleviate some of the concerns around a piecemeal approach to systems integration and the associated complexities of tying together a patchwork of vendor systems.

“That’s a really big challenge because the resources are not there - that’s not something that ONC is necessarily funded to do. And it’s something we work with our partners at CDC to make sure that they understand the ONC vision so as they help local and state health departments’ development infrastructure they can work towards the standards as well. And one of the projects that they’re currently doing is, working with ASTHO and NAACHO to build a public health community platform where a set of services - could be available in a centralized fashion so that EHRs just have one place to interface with the community health platform and then public health could take advantage of that infrastructure and have the appropriate access to EHR vendors or the providers that are using those products within their communities. One of the things that we learned from meaningful use Stage 1 and 2 with say immunization reporting was, even though we had a set of standards for those transactions, having every health department build their own interface still caused a lot of problems with vendors. They still had to build 50 or more separate interfaces for each of those states even though they were following standards and interfaces were similar - having 50 different interfaces to work with still caused a lot of problems with the vendors. So this public health community platform could solve two problems, providing the infrastructure for public health and making things actually easier as well for the vendors so more providers could participate in these types of interactions.”
The key informant interviews and sample commentary not only provided the context to the survey data, but a practical feel for the realities on the ground and the challenges faced by public health officials in the evolving electronic landscape. Moreover, the key informants provided a basis for recommendations to public health agencies to take advantage of HIE.
CHAPTER 5: DISCUSSION

The Health Information Network of South Texas is being developed to bring together a wide group of providers, hospitals, health departments, and other community organizations, with one of its key objectives being to improve public health outcomes. This research aimed to assess and understand how local health departments in South Texas can potentially attain effective use of electronic health information exchange provided by HINSTX to support community level chronic disease surveillance. The LHD survey attempted to provide baseline profiles of current LHD capabilities to perform chronic disease surveillance across the three domains of people, process, and technology. The survey was further supplemented with interviews of LHD officials to better understand not only the context in which chronic disease surveillance occurred, but importantly, to describe the potential gaps and opportunities for improvement in effectively using HIEs, particularly in resource constrained settings.

The results from this research suggest that there is an interest on the part of LHDs to make use of emerging data streams from HINSTX specifically and generally from HIEs. The development of HIEs and state activities to promote provider adoption of EHRs and HIEs along with federal Meaningful Use criteria specifically targeting population health improvements have influenced local public health activities over the past four years. Further, state and local HIE efforts such as HINSTX have been a catalyst for LHD engagement in planning for and inclusion of public health functions in the development of electronic exchanges. Specifically, this development has included two LHD Directors sitting on the Board of HINSTX, helping drive
organizational preparations to utilize HIE, such as the development of work flows and processes to manage new electronic data streams, and development of policy and plans.

However, given the largely rural area covered by HINSTX and the handful of full-service LHDs that perform surveillance functions, it is unclear how HIE could be used for surveillance functions where this function is not currently performed. Our results suggest that HIE developments in general have brought about a recognition of the specialized nature of public health and disease surveillance. LHDs and state officials have also recognized that there are only a limited number of personnel who have the skills required to work with and effectively utilize HIE within the context of public health surveillance functions. Moreover, there is anecdotal evidence from our study that LHDs and the state have been ramping up training efforts for public health staff triggered by both federal and state health IT initiatives and subsequent growth of EHR use and HIE developments. Building on the finding in this research, recommendations have been developed but we recognize these will need to be further evaluated given the limitations of the study.

Aim 3
Develop strategies to help guide the filling of gaps in local health department’s surveillance capacity.

Recommendations

We have developed several recommendations for better utilizing the opportunities presented by the emerging electronic public health information exchange environment. These recommendations were vetted with several key stakeholders, including the Texas State HIE office, HHS’s Office of the National Coordinator, and LHD and Regional Health Directors. However, these recommendations need to be further explored in light of the small scale, localized nature of the study along with other study limitations.
The discussion below highlights recommendations framed by people, process, and technology, and implementation approaches for these recommendations. All of the respondents agreed that there is a need to ramp up local health department personnel with training and skills required for effective public health surveillance within an increasingly electronic environment. As such, there is an even greater existing and future need for personnel development and staff augmentation in local health departments. Although electronic health information exchange offers potentially increased efficiency to public health surveillance, even in the most sophisticated systems, human input will still be a substantial and significant requirement into the overall surveillance process, as some steps cannot automate out human judgment, interpretation, and application. Figure 3 below depicts an optimal balance of people and technology into the routine public health surveillance process. Subsequently, the recommendations below are targeted towards addressing key people, process, and technology challenges identified by respondents.

Figure 3: Ideal balance of people and technology inputs into public health surveillance

Source: Adapted from CDC highlighting People, Process, & Technology. The width of the arrow indicates the relative people and technology inputs into each activity.
Building on the themes identified from the surveys and interviews, we developed four key recommendations to address the challenges faced by LHDs to effectively utilize HIE for chronic disease surveillance. Table 10 below summarizes the themes, gaps, sample informant quotes, and key recommendations.

**Table 10: Summary of Themes, Gaps, Informant Quotes, and Key Recommendations**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Domain</th>
<th>Gaps</th>
<th>Quotes</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Staff skilled in analyzing large volumes of clinical data that are realized by HIE</td>
<td>People</td>
<td>Lack of skilled staff</td>
<td>“We’re worst prepared with people”</td>
<td>1. Develop structured efforts for capacity building (LHD internal) and skills development of personnel</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Lack of personnel or personnel that are trained in technology”</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“You really have to have your hospitals your doctors your public health - you have to have everybody at the table altogether, or you’re not going to make any progress”</td>
<td>2. Establish a local informatics collaboration (inter-organizational) with clinical providers, HIE, and community groups</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Clearly articulated laws and regulations</td>
<td>Process</td>
<td>Chronic disease not prioritized and insufficient laws and regulations for electronic exchange</td>
<td>“Yes there is a gray area”</td>
<td>3. Develop approaches that may provide an interim bridge for fully utilizing HIE for public health surveillance until overarching state legislation is enacted</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“They don’t address may be correctly at this point, electronic information to be received”</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Overall health IT strategy must be developed and implemented</td>
<td>Technology</td>
<td>No overarching public health IT strategy to integrate HIE</td>
<td>“You can’t do any of that until you build a standard system that’s interoperable”</td>
<td>4. Develop health department enterprise architecture plans that will serve as the blueprint for how agency operational structures are optimally defined, in both business and technological environments</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Set uniform standards so everyone is working together”</td>
<td></td>
</tr>
</tbody>
</table>
Gap: Trained staff skilled in analyzing large amounts of clinical data from HIE must be available to make it useful.

Results from the survey and a key theme from interviews with LHD staff found gaps with both the availability and capacity of local staff to analyze data received through the HIE and transform it to useful information that can be understood and used by all relevant stakeholders. Importantly, it was noted that there is not enough local personnel capacity to act to address the issues that are found, particularly with chronic disease surveillance. With ever increasing automation of data streams, personnel availability and expertise, is increasingly critical to identify potential cases of disease, diagnosing disease, analyzing and interpreting data, and disseminating results to all stakeholders (CDC, 2012).

Recommendation 1. Develop structured efforts for capacity building (LHD internal) and skills development of personnel.

Developing local level expertise and increasing human resources are essential steps in strengthening LHD capacities for chronic disease surveillance. This development entails cross-training personnel where there may be limited capacity to hire additional staff or developing specialized staff to serve in aspects of chronic disease and informatics, if the budget allows for additional staff. Though training is an essential component, it must be coupled with structural (e.g. HR policy, unions, etc.), procedural, and organizational steps that will create the appropriate environment and stimulus for personnel, not only to better understand how to interpret chronic disease data, but also how to respond. This understanding is especially important given that chronic diseases are typically much slower, complex, and diffuse and are not necessarily seen as a “crisis” with a short-term solution, such as that with a better understood infectious disease response cascade. However, the common response protocol for infectious diseases, i.e. case
definition, risk factor analysis, and risk factor control, are applicable and underused for chronic
disease management (Frieden, 2004).

Strategies that may help to support aspects of LHD personnel capacity development include:

- Define, formalize, and implement human resources policies and directives specifically for
  chronic disease surveillance. While the identification of chronic diseases and the use of
  HIE as a priority for LHD surveillance were made clear by respondents, use must be
  supported by personnel capacity development policies that will put in place staff with the
  right knowledge and skills. It may be possible to augment currently available LHD
  epidemiological skills with health IT data extraction and analysis experts outsourced to
  HINSTX.

- Develop, revise, and advocate for applied epidemiology training programs that
  incorporate the use of public health informatics and hands on learning by the use of
  computer aided public health analytics.

- Expand the use of existing state training programs and increased promotion of models
  that builds on the state health department sharing of staff, expertise, and strategies to
  widen and strengthen intra-state networks and foster the creation of local-state partner
  chronic disease response teams.

- Integrate electronic surveillance methodologies into existing continuing education public
  health training, and longer term specialized public health training and incorporating
  continuing education competency based training methods.

- Develop or strengthen links between the Texas Department of State Health Services and
  academic institutions to ensure clear articulation coupled with collaborative LHD
  development of curricula and training based on short and long term skills gaps. This
development could include co-funded academic internships, collaborative, residency programs, work-study, etc. focusing on public health informatics and epidemiology of chronic diseases.

Recommendation 2. Establish a local informatics collaboration (inter-organizational) with clinical providers, HIE, and community groups such as the Coastal Bend Diabetes Initiative, and academic institutes such as Texas A & M--Corpus Christi through a dedicated work group with the LHD serving as the neutral convener targeting prioritized chronic diseases.

Respondents noted some level of collaboration that already existed with various local organizations however, there was no organized effort to merge these collaborations with the interface to HIE development and leveraging this work to target specific chronic disease challenges in South Texas. As noted by the Public Health Informatics Institute, “Coalitions usually form when a lead agency or convener group responds to an opportunity, threat, or mandate. Many communities are being challenged to develop health information exchange, but leadership has not emerged” (Livingwood et al., 2009). The LHDs can serve this vital role however; the PHII goes on to caution that this role “will depend extensively on their credibility within the community as a competent and capable organization, as well as their previous experience as a team player.”

While this research did not examine the LHDs’ community standing and reputation, we believe that there is a sufficient gap in available personnel resources and necessary skills that at minimum a dedicated work group could at least begin exploring approaches to leverage and share available resources while increasing knowledge and information sharing. The initial goals of this group could include:
• LHD serves as a key convener bringing together public health agencies with HIE entities for effectively reconciling and integrating technology approaches and vendors with a focus on public health surveillance functions

• Gauge the adoption, diffusion, and use of EHRs by clinical care providers and identify existing gaps and opportunities particularly as they relate to the use of these systems for chronic disease management

• Explore approaches for the sharing of electronic health information via the HIE, impacts on current business processes, and required business process modifications to improve both care delivery and overall community health for target chronic diseases

• Establish a local forum for the community to work together on identified joint projects, funding opportunities, and community awareness and advocacy for use of electronic health information

• Develop joint training curricula and programs for staff and opportunities to collaborate in co-located training sessions

Strategies that may help to support LHD collaboration development include:

• The precise organizational structure should be carefully crafted based on the unique social, political, and economic circumstances in South Texas. This design may initially mean establishing this group under the current HINSTX governance committee structure with an LHD director appointed as the lead, but perceptions of any potential bias should be factored in the selection i.e. large vs. small LHD.

• We did not do an assessment of local health care provider competition in the South Texas area. However, positioning an LHD in a leadership role within the collaborative will be better achieved and sustained if it serves as the central mediator and convener with the confidence
of the community as an unbiased mobilizer of personnel and resources centered on improving outcomes of priority chronic diseases.

- In keeping with the role of the neutral convener, the LHD cannot take sides or be perceived as taking sides which is detrimental as a facilitator and undermines efforts to develop trust and understanding.

- All respondents reiterated the firm belief in the potential of HIE for public health and this potential can serve as a springboard for advocating the community-wide use of electronic information exchange and establishing credibility as the community center for others interested in electronic health information exchange.

- While there is no fixed size for this group, a balance of organizational complexity, speed of decision making, as well as effective influences of each stakeholder on outputs should be considered. Different levels of membership should be considered given that certain stakeholders will have more direct influences on outcomes versus others who may have more indirect influences such as those related to overarching policy.

**Gap: Clearly articulated laws and regulations to help enable the full and effective use of HIE.**

Results from the survey and interviews consistently noted a significant gap in current chronic disease surveillance efforts with feedback on community health status ranging from months to years which was considered unacceptable. Subsequently, it was noted by respondents that engagement with local HIE efforts is seen as a way to shorten the current lengthy feedback loops on chronic disease and provide more real-time and actionable information for prevention and care interventions. However, apart from personnel challenges, the lack of legal authorization
to report through electronic information exchange has not been clearly articulated by the state as current legislation does not address electronic information transfer.

In addition, the pace of health information technology adoption and diffusion such as EHRs has accelerated in Texas aided in part by HITECH funding for provider adoption. Since 2011, more than 6,200 eligible health care providers and 285 eligible hospitals have implemented EHRs (Texas Health and Human Services Commission [THHSC], 2013). In addition, the Texas state Health and Human Services Commission (HHSC) is developing an electronic clinical gateway to collect clinical and administrative data from the EHRs for Medicaid clients. Notably, eligible clinical providers and hospitals can opt to report key public health measures, such as immunization records, electronically via the HIEs with public health reporting as a key component to the HIEs.

While local and state health information technology efforts have made significant progress, the current policy and regulatory environment has not kept pace. Though recent Texas state legislatures efforts have helped to accelerate the implementation of the state HIE framework (S.B. 1643, 83rd Legislature, Regular Session, 2013), HHSC has reported on numerous regulatory barriers that echo in detail, sentiments expressed by LHD respondents in regards to the still lingering legal gaps to support HIE for public health. Some of these issues include (THHSC, 2013),

- Challenges surrounding the ability for state agencies to share health information to improve the quality of healthcare provided to Medicaid patients. Agencies need to share information with Medicaid providers and facilitate transition of care to clients who seek treatment elsewhere. Senate Bill 7, 83rd Legislature, Regular Session, 2013, begins to address this challenge. However, additional statutory barriers still exist, such as the
inability of sharing much of the Texas Department of State Health Services (DSHS) public health information.

- A recent bill that would have allowed the state to begin exchanging information with each other and other entities using nationally recognized interoperability standards was not able to pass during the most recent legislative session.

- Another bill that was unable to pass would have clarified DSHS statutes enabling access to certain public health information.

**Recommendation 3. Develop approaches that may provide an interim bridge for fully utilizing HIE for public health surveillance until overarching state legislation is enacted.**

While there may not be an immediate legislative fix for the current legal gaps that exist to support HIE for public health, there are still approaches that could be explored for viability within the community. There are current regulatory challenges for the implementation framework of HIE for public health but this challenge should not be seen as insurmountable, particularly in light of the momentum and energy that has been achieved with the work of HINSTX to date. The LHD led informatics collaborative is the ideal forum for the development of approaches to accommodate the essential public health information needs for chronic disease surveillance.

Some strategies for interim legal approaches to support HIE for public health include:

- Collaborate with HHSC and DSHS on specific elements of information to be exchanged and assistance in interpretation of current legal code and identification of potential areas that may not have the same restrictions as a fully implemented HIE.
• Participate in and advocate on any state level efforts and forums that are in the process of developing policies for electronic health information exchange.

• Explore patient consent models i.e. opt-in, opt-out, that can accommodate all of the information that is needed for chronic disease surveillance facilitated by public health while providing the broadest inclusion of patient population covered by the HIE.

• Work with HHSC to determine what possibilities there maybe to modify current Medicaid provider contracts in order for LHDs to obtain the necessary clinical data for chronic disease surveillance through the HIE.

**Gap:** Overall health IT strategy to coordinate and integrate the priorities, goals, and objectives of various public health information technology initiatives to effectively use HIE.

All respondents indicated general use of data standards such as CDC’s Public Health Information Network (PHIN) and National Electronic Disease Surveillance System (NEDSS), as well as HIPAA exchange standards, it was noted that actual databases and systems that have developed piecemeal with many systems at the LHD are unable to exchange data. While there has been an increased availability of commonly defined data standards, most importantly consistent implementation, particularly with modernization of legacy systems, continues to be a challenge in achieving true bi-directional electronic health information exchange (interoperability).

Moreover, while health care providers have received incentives to implement certified and standards-compliant EHRs, public health and LHDs in particular have struggled with keeping pace to upgrade their technology infrastructure to support capture and aggregation of clinical data streams as mandated by HITECH “meaningful use” reporting criteria. Challenges such as inconsistent medical terminology, variable clinical records and data storage structures, as
well as a multiplicity of proprietary methods introduced to facilitate interconnection and communication between vendor specific IT systems.

In addition to data standards challenges, respondents (while recognizing the potential benefits of HIE for public health) recognized that the introduction of HIE data for public health is a major shift in current business processes and technology infrastructure. Major technological change can be challenging coupled with transforming existing, largely manual, public health work flows and information systems only add to the complexity. The substantial upfront commitment and investment of resources is daunting and movement to interoperable public health surveillance information technology from multiple, stand-alone, siloed systems involves unique challenges. These challenges include changes such as, setting up automated data-collection streams from HIE data sources, which is different from manual data abstraction from health-care records.

At the same time, issues surrounding data quality, process automation, work flow design, and system validation must all be comprehensively addressed (CDC, 2012). These challenges must be tempered by clearly defined goals and objectives for chronic disease surveillance, tightly linked to new information systems and informed by careful analysis of current health department business processes and the necessary business process reengineering required to fully leverage the new electronic environment.

**Recommendation 4. Develop health department enterprise architecture (EA) plans that will serve as the blueprint for how agency operational structures are optimally defined, in both business and technological environments along the continuum to transitioning to an electronic public health surveillance model.**

The concept of using enterprise architecture to describe an organization has been around since the 1980s but only more recently has been suggested for public health (United States
Government Accountability Office [GAO], 2010; Public Health Informatics Institute [PHII], 2009). As defined by the Government Accountability Office (GAO, 2010),

“An EA provides a clear and comprehensive picture of the structure and substance of any purposeful activity, whether it is an organization (e.g., a state health department or local health agency) or a mission area that cuts across organizational boundaries (e.g., chronic disease information sharing or immunization registries). An EA can be viewed as a blueprint for organizational transformation and IT modernization.”

As such, the EA will serve to outline an organization’s business, business processes and supporting IT infrastructure, and shows how they all relate, with the goal of improving organizational efficiency and effectiveness for the purpose here of chronic disease surveillance. The Texas Health Service Authority (THSA) has produced a comprehensive state level “Enterprise Architecture Blueprint” that provides (Texas Health Services Authority [THSA], 2011),

- An overview of the THSA vision for Texas HIE
- Identifies use cases which align with the Texas HIE desired capabilities
- Provides a functional blueprint for technology components and interfaces required at the clinical, local HIE, and state levels required for the next 1 to 2 years
- Identifies and documents for the planning considerations for years 3 to 4, and a very high-level strategic direction for years 5 to 6
- Maps process flows for the use cases to the technology components and interfaces described in the blueprint

Furthermore, the blueprint also specifies how public health services will interface and function within the overall architecture along with requisite information systems principles for IT
integration, standards, and privacy and security specifications. Although, public health chronic disease surveillance is not specifically cited as a use case, two other related public health use cases are highlighted, public health lab results reporting and public health quality reporting. Beyond this reporting, the blueprint notes, “Above a certain set of core functions (i.e. security and privacy), it will be largely the responsibility of the providers and the Local HIEs to determine which components they would like to implement and how to design their solution” (THSA, 2011). Subsequently, it is imperative that local health departments work to develop local EAs to guide their efforts.

Some strategies to guide the development of local health department EAs include:

- Create an internal LHD EA taskforce (HINSTX may be able to provide dedicated staff and expertise to assist in this effort) with agency leadership buy-in to develop an approach and process tailored to the LHD’s needs. This process need not be an overblown effort, rather a targeted effort focused on narrowly defined key opportunities coupled with developing strategic priorities for achieving the limited objectives. This development should be appropriately aligned with the local inter-agency informatics collaborative, as well as the state blueprint wherever possible and appropriate, national strategic priorities.
- Identify and formulate an approach and priorities for enabling integration of related data, such as maternal and child health, immunizations, infectious diseases, etc. This priority list should include a review of both legacy data systems and new data systems and streams related to HIE and what agreed upon standards will be used.
- Identify and review which systems including legacy systems would provide the greatest value in achieving the surveillance objectives in light of emerging HIE data and define an overall path for getting there.

- Identify how current and “to be” systems could better serve support specific LHD functions. This service should include visual mapping of business processes and identification of current challenges and inefficient work processes. These business processes should then be redesigned with workflows aligning information systems to better support effective and efficient work.

**Limitations of the Research**

Future research will help improve on several limitations of this research. First, this research presents only a small descriptive sample of the potential utility of HIE that is not fully operational yet. Studies utilizing a broader sample of LHDs with both before and after HIE operations initiation are needed to better describe the use case of HIE for chronic disease surveillance and the potential impact on surveillance functions. In addition, results may be influenced by selection bias, in that larger LHDs providing the range of public health service functions, large staff, and significant technology infrastructures actively engaged in exploring the use of HIE and volunteered to serve on the board of HINSTX.

Still, other smaller LHDs did have some knowledge and awareness of HIE and may be exploring opportunities to prepare themselves with needed people, processes, and technology to utilize HIE more effectively. Also, the findings from this research are limited to South Texas LHDs which are not representative of all local health departments in Texas or in the U.S. Beyond this, qualitative research findings are not commonly generalizable to the larger population. This limitation is due in part to limitations in the total sample for observation, in this study, a single
HIE and one local health department and one Regional health department with a limited number of interviewees.

This sample is further limited by problems of temporal sampling and situational (Marshall, 1996) influences, especially in a nascent setting where the HIE landscape is very dynamic and numerous policy and fiscal influences at both the state and federal level are still evolving. As noted by Yin (1994), the goal of such studies is, “analytic generalization” rather than “statistical generalization.” The former expands and generalizes theories and the latter specifies frequencies (Yin, 1994). While these limitations cannot be fully eliminated, for this project we used different data sources, such as surveys and in-depth interviews with key informants at multiple levels, local, state, and national, to help support and cross-validate findings.

There are additional limitations, which are associated with data sources used for this research. While the indicators used to describe LHD surveillance capacity brought together aspects of a people, process, and technology model of information systems, the specific indicators are just one interpretation of describing capacity since no definitive, detailed, and accepted model of public health surveillance capabilities is currently available. In addition, the study relied on LHD self-reported survey data that has not undergone external validation. Our study also relied on the HINSTX Executive Director’s relationships for direction and access to LHD, state, and national officials for key informant interview introductions encouraging them to participate in the interview and facilitating communication and may have introduced some personal bias. Any bias introduced due to the HINSTX Executive Director’s personal relationships was mitigated by including additional key informants from the same organizations who did not have personal relationships with the Executive Director.
Furthermore, these data represents information at one point in time that in part represents some projections or goals as opposed to actual status since the HIE is not fully available as yet. Efforts were made to take great care in survey construction by utilizing a reputable survey tool, Qualtrics, and pretesting to minimize systematic differences in respondent interpretation. However, there may still have been differences in how respondents interpreted questions. Finally, interviews were limited to health directors and relevant surveillance and technical staff from one full service LHD and one Regional health office that responded to the survey. While the other LHDs in the HINSTX service area did not perform the compliment of public health functions such as surveillance and were not included, future research efforts should include a representation of very small limited service LHDs to explore broader contextual challenges for diffusion and use of HIE in resource limited settings.

Benefits of the Research

One benefit of this research is the development and use of a new instrument to gauge health department capacity related to surveillance, which could be further refined and developed for future studies. While the sample of LHDs is small, it provides a baseline data for pre HIE use and provides a starting point to explore how the activities of these health departments change as the HIE begins to operate and more patient level data becomes available. In addition, the findings from the research are serving to inform state health department and state HIE organizations in their development by providing in-state experiences of challenges and opportunities for including LHDs in leveraging HIE for population health. The population health aspect has become increasingly crucial as part of the federal Stage 2 Meaningful Use criteria for EHR purchase subsidies for providers, which require the ability of EHRs to be able to submit agreed upon chronic disease metrics for conditions such as diabetes, hypertension, and others.
Critical to this criterion is the ability of LHDs to be able to receive not only electronic data submissions from provider EHRs, but also to manage and analyze these new data streams in cohesive community level disease surveillance.

However, this research found that only one LHD was currently capable of performing any of the Stage 2 functions. As such, the HIE, once operational, offers a unique opportunity to explore not only the technical connectivity expedience offered to LHDs to meet Stage 2 requirements, but also to track the ability of LHDs to ramp up supporting personnel and processes to accomplish surveillance functions. Subsequently, these research findings contribute to the current body of evidence within public health informatics research in that we were able to document the HIE public health use case for chronic disease surveillance in one state using a novel health department surveillance capacity instrument.
CHAPTER 6: PLAN FOR CHANGE

As defined by the National Association of County and City Health Officials (NACCHO, 2006), LHDs are the foundation of the local public health systems that comprise public- and private-sector health care providers, academia, business, the media, and other local and state governmental entities.

Furthermore, surveillance is a cornerstone in assessing community health status, especially chronic disease, which is more diffuse. As such, the need for LHDs to become more actively involved in public health informatics was recently highlighted by the rapid acceleration of electronic information systems adoption such as EHRs and HIE in health care, triggered by and large from ARRA/HITECH incentives coupled with “meaningful use” criteria. Subsequently, LHDs have been identified as the nexus for information exchange (Vest et al., 2012). However, this study has helped to illustrate some of the lingering gaps that remain in the ability of LHDs to keep pace with the deluge of automation that has taken place more broadly in the health care industry.

A recent study by Vest et al (2012) found that the use of public health informatics uncommon and at their current information systems capacity levels, LHDs will struggle to play a meaningful role in the integration and exchange of health information. Indeed, the final report of the Turning Point National Excellence Collaborative for Information Technology (2005) concluded that “Unlike private industry, public health has not valued information systems technology as a key ingredient to success. Rather, the practice of informatics is essentially an
afterthought.” Effective chronic disease surveillance hinges on the ability of LHDs to harness the newly available, more timely, granular, and accurate information at the population level enabled by HIE. But for LHDs to exploit these electronic resources, they will have to bridge the capacity gap.

Findings and recommendations from this dissertation will be presented to the Governing Board of the Health Information Network of South Texas where two LHD executives are also members. Furthermore, an executive summary with recommendations will be provided to LHD executives in the HINSTX service area, as well as the leadership of Texas Health Service Authority and Chief Executive of HIE Texas.

Additionally, options for publication in a peer-reviewed journal will be explored. The researchers fully acknowledge that the findings and recommendations developed from this study are in no way intended to be a panacea for the gaps that exist. Therefore, the plan for change emphasizes the recommendations as a starting point for internal discussion with LHDs and externally between, not only HINSTX and participating LHDs, but more broadly as a catalyst for discourse on building public health informatics capacity around the shared concern of controlling chronic disease nationally.

Internally, LHDs need to evaluate their own information systems capabilities using the people, process, and technology model. This evaluation should include assessment of current capacity and strategic outlook on the desired future state with emphasis on tactical steps to achieve near-, mid-, and long-term objectives. Externally, the findings should help initiate discussions around immediate LHD informatics gaps with HINSTX and state agencies, as well as development of a local collaboratives around public health informatics. At a minimum,
highlighting of LHD informatics gaps may serve to inform further HIE infrastructure development plans and potential targeting of additional state level support.

Nonetheless, we recognize that the process of change, particularly for modernization and transformation of information systems is notoriously perilous and complex, with a litany of evidence of shortcomings in health care (Marchibroda, 2007; Chaudhry et al., 2006; Overhage et al., 2005; Rubin, 2003; Starr, 1997; Wenzlick, 1997, Scott, 1993). The initial investments in time, human capital, process reengineering, and technology procurement are difficult and daunting to commit to. Notwithstanding the numerous technical challenges, a survey published in *Work Study* noted that leadership was a key facilitator in large transformation projects (Zairi & Sinclair, 1995). With this in mind, we recognize that any plan for change is merely “shelfware” to use IT jargon for software that is never used, unless the leadership exists to internalize and drive execution and deliver concrete outcomes. As such, the organizational change theory of John Kotter presents a tried and true approach for translating the findings from this study into action.

Kotter’s eight key insights into organizational transformation provide a sound foundation for a change (2002):

Kotter’s framework for change is organized into three distinct phases, 1) “creating a climate for change” and includes steps 1. increase urgency, 2. build guiding teams, and 3. get the vision right; 2) “engaging and enabling the whole organization” consists of steps 4. communicate for buy-in, 5. enable action, and 6; and 3) “implementing and sustaining the change” encompasses steps 7. don’t let up and 8. make it stick. Importantly, Kotter’s framework for change is underpinned by the need for a strong leader to facilitate the eight steps or as he notes (Kotter & Cohen, 2002),
“change, by definition, requires creating a new system, which in turn always demands leadership.”

Overlaying the people, process, and technology model for IT organizational change, Kotter has stressed the people aspect of transformation. While there are more easily quantifiable process and technology gaps i.e. lack of legislation, IT standards; more subtle and less measureable are the people gaps. From the study respondents and the literature, it is evident that the people aspect is the biggest single challenge to change implementation. If we are to succeed in transforming LHDs into modern IT enabled organizations, this transformation will necessitate leadership decisions and actions designed to help people embrace and maximize new processes, technology and ways of working. As the plan for implementing the recommendations was developed, Kotter’s work served to provide the overarching driving principles with which the recommendations and suggested strategies be deployed to help increase chances of successful organizational transformation. As such, each of the recommendations and suggested strategies should be tempered by all of Kotter’s organizational transformation steps; however we have highlighted some steps that may be particularly useful with the associated recommendations in Table 11.
<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Strategies</th>
<th>Kotter’s Change Steps</th>
</tr>
</thead>
</table>
| 1. Develop structured efforts for capacity building (LHD internal) and skills development of personnel | • Define, formalize, and implement human resources policies and directives  
• Develop, revise, and advocate for applied epidemiology training programs  
• Expand the use of existing state training programs  
• Serve as the central convener for local stakeholders and role model of the new IT enabled organization | • Increase urgency  
• Build guiding teams  
• Get the vision right  
• Communicate for buy-in  
• Don’t let up  
• Make it stick |
| 2. Establish a local informatics collaboration (inter-organizational) with clinical providers, HIE, and community groups | • Define, formalize, and implement human resources policies and directives  
• Develop, revise, and advocate for applied epidemiology training programs  
• Expand the use of existing state training programs  
• Serve as the central convener for local stakeholders and role model of the new IT enabled organization | • Increase urgency  
• Build guiding teams  
• Get the vision right  
• Communicate for buy-in  
• Don’t let up  
• Make it stick |
| 3. Reevaluate current disease surveillance priorities within the context of potential HIE data stream and develop an interim bridge for fully utilizing HIE for public health surveillance until overarching state legislation is enacted | • Perform an evaluation of current LHD disease surveillance priorities utilizing either a contractor if funds or grant are available or an internal project team with allocated time dedicated for the evaluation.  
• Collaborate with HHSC and DSHS on specific elements of information to be exchanged  
• Participate in and advocate on any state level efforts and forums  
• Explore patient consent models i.e. opt-in, opt-out  
• Work with HHSC to determine what possibilities there maybe to modify current Medicaid provider contracts | • Enable action  
• Create short-term wins  
• Communicate for buy-in |
| 4. Develop health department enterprise architecture plans that will serve as the blueprint for how agency operational structures are optimally defined, in both business and technological environments | • Create an internal LHD EA taskforce with agency leadership buy-in to develop an approach and process tailored to the LHD’s needs  
• Identify and formulate an approach and priorities for enabling integration of related data  
• Identify and review which systems including legacy systems would provide the greatest value  
• Identify how current and “to be” systems could better serve support | • Build guiding teams  
• Enable action  
• Create short-term wins  
• Communicate for buy-in |
Creating a Climate for Change

Given the increasing prevalence of chronic disease in South Texas, the LHDs are best poised to be the neutral conveners and leaders in driving the changes necessary to take advantage of HIE for surveillance. That being the case now is the time to create a sense of urgency so that people can shift from ‘business as usual’ and break through the resistance to change. Creating this urgency will involve helping people visualize and understand first hand why a change needs to occur. As such the recommendations presented here should be couched within a clearly articulated vision or direction. This vision should be built on common rally points such as, targeting the management and control of diabetes for the population of South Texas (Diabetes Care Project, 2013; Coastal Bend Diabetes Community Coalition, n.d.).

Critical to creating this urgency is the creation of a coordination team, which stems from the informatics collaboration team as the natural champions for change. The team members need to have the knowledge, credibility, influence, and skills required to mobilize change (Kotter, 1996). Things to consider when selecting this group of advocates for change (The National Learning Consortium, 2013):

- Have a full understanding of goals, objectives, and overarching visions of the future state and are dedicated to achieving these goals
- Are able to translate and interpret the why, the how, and the urgency, and then clearly communicate and diffuse this interpretation to LHD staff and other stakeholders
- Have a deep knowledge of LHD operations, work flows, and processes
• Have a people management skills and the ability, to some extent, to recognize
  individual strengths of each team member, how each is useful in various phases of
  the change implementation and can engage needed individuals when needed

  The purpose of the team is to be able to coordinate behavior change, especially building
conviction and to build momentum around the need for change. This coordination should be
  closely linked to developing a vision and strategy that is clear and defines a vision that is shared
by all stakeholders. The result should be a compelling statement that clearly articulates what they
  are trying to achieve, which will then help make sense of subsequent underlying strategy needed
to deliver the outcomes. The vision should include a consensus around what the future state
  looks like with clear and measurable objectives such as, reduce the proportion of persons with
diabetes with an A1c (a commonly used diabetes diagnostic measure of blood sugar control over
  the past 2 to 3 months) value greater than 9%.

_Engaging and Enabling the Whole Organization_

  While the literature review noted several studies that cite the potential value of HIE for
public health surveillance, there is very limited evidence of practical use cases in peer-reviewed
literature. Nonetheless, the ARRA/HITECH legislation and the associated “meaningful use”
criteria has envisioned public health as a keystone in improving population health as the use of
health IT is expanded in the health care delivery setting. In addition, it was clear from this
research that public health leaders have embraced the health IT vision and are supportive of
diffusing this technology into their organizations. However, this study has shown that there is a
gap that exists between national public health informatics aspirations and actual achievements.

  Building on creating the climate for change, it is essential that the narrower vision
developed by the coordination team and be communicated frequently and convincingly to all
participatory groups. This communication must involve words and actions that exemplify meaningful steps towards achievement of the vision. For example, some novel ways to make this desired future state and vision more real would be to use vendor demonstrations of HIE data feeds, videos, or walk through of new work flows with HIE data, that align with how the LHD operates. Other approaches, include having LHD staff go on site visits to other LHDs in the state where HIE has been successfully integrated and is used for routine public health functions. This approach should be backed up with continuous engagement and dialogue with stakeholders to build commitment and trust in regular coordination team meetings assessing progress on discrete deliverables. Engaging LHD staff in helping re-design work flows and HIE training efforts is a good way to empower stakeholders while embedding them into the change.

Furthermore, the LHD staff’s firsthand knowledge, expertise, and experience, are indispensable in cultivating ideas for best implemented practices since they ultimately make up the organization. Some LHD staff engagement activities could include participation in the work flow design, HIE implementation activities at LHD, and evaluation of the progress of HIE deployment. To help keep the momentum, creating short term wins is a critical component to this phase and helps provide short term visible and achievable outcomes of what can be a lengthy change process. This outcome could include achievement of successful HIE data flow into designated LHD systems, workflow or process change in preparation for new HIE data, setting up a training session for HIE data, and developing an analytical approach for identifying diabetic patients A1c’s greater than 9% and creating a feedback loop for provider follow up.

**Implementing and sustaining the change**

This last phase of the change process stresses making the changes a permanent and meaningful transformation. Given that HINSTX is in its initial deployment stages and is still
early in the overall process of developing HIE data products and services this last step will be some time in the future. As such, the suggested steps here are meant to be high level guidance and considerations for keeping the future state an actively sustained and enduring transformation that is continuously monitored. In other words, the introduction of HIE to the LHD should not be considered a onetime deployment for all the information challenges that are faced by LHDs. On the contrary, the introduction and LHD interface to the HIE is a first step in beginning to explore the potential opportunities and use case for the public health.

**Partnering for Success**

Finally, coupled with strong leadership for organizational change, LHD collaborations are the required bedrock for long term growth and sustainability of public health’s engagement with informatics. As Kanter (2011) notes, “Leaders might be singled out for their accomplishments, but the best of them walk hand in hand with strong partners.” Kanter further notes that having the best partnerships is not a *result* of success but an essential *part* of success for an organization. This statement holds especially true in the public health community where limited resources are common place and a “go it alone” mentality would be untenable by any LHD leader. While public health has a long tradition of community collaboration as a mainstay, Kanter (2010) offers 15 steps to ensure effective inter-organizational collaborations and likens them to modern marriages. Sample strategies or approaches for LHD leaders are noted as well.

1. Be open to romance, but court carefully.
   - Given the limited resources generally available in the public health community, LHD collaborations with any single or multiple partners should seen as a part of the solution and tempered by the reality of what each partnership can and cannot offer.

2. Know yourself. Build your strengths.
   - Identifying, developing and retaining key LHD personnel will go a long ways in building personnel capacity that is needed for maximizing HIE for surveillance.
3. Seek compatibility in values.
   - Collaboration must hold more than just material value and be more enduring to overcome inevitable challenges and changes and be built on mutual trust. As echoed by Kotter, LHD collaborations including inter-agency work groups must be built on a shared vision and values.

4. Treat the ‘extended family’ respectfully.
   - Building LHD leadership relationships and rapport are important but the same relationship must also include other people and organizations that are already extended members of partner organizations (i.e. academic partners, professional organizations, disease consortiums, etc).

5. Put the lawyers in their place.
   - LHD Directors, state public health leaders must establish direct leader to leader relationships which are critical and should not be substituted with third party professionals (i.e. consultants, lawyers, etc).

6. Vow to work together until business conditions do us part.
   - Begin with a small first project such as joint staff training on HIE data analytics and begin exploring other areas of collaboration, be cognizant of changes in operating conditions, and remain friends if changing conditions require a graceful exit.

   - Do not assume formal agreements will anticipate everything and interpretations will vary-be flexible. While formal contracts or Memoranda’s of Understanding may provide a general structure for LHD collaborations and inter-agency work groups they should not be overly prescriptive. This is particularly important given the lesser understood implications of HIE use for surveillance.

8. So keep communicating, face-to-face.
   - Even after partnerships are made official, partners’ leaders must continue to engage routinely and personnel must be dedicated to monitor the relationship and ensure effective participation.

   - While LHD alliances may initially begin with leaders, more people must be involved. Increasing the feelings of inclusion with face to face interactions and better knowing one another will make partnership activities easier to implement.

    - Collaborations can be more active when there are some structures and processes developed (i.e. LHD informatics collaborative that includes some formal governance, joint project team, etc.) to serve as organizational bridges.

11. Respect differences.
LHD partnerships are in part seeking to build on partner organization differences and capabilities that may not exist within any single LHD. However, these unique sought after capabilities (e.g. pre-defined) disease registries may come along with other unexpected differences such as personal styles, motives, goals, operating methods. Respect must be maintained and an effort to understand these unexpected differences and transcend them is critical

12. Teach partners.
   - Learn from each other and promote and atmosphere of learning.

13. Be prepared to change yourself.
   - LHD partners must be willing to influence and be influenced by one another. To make partnerships work, they need operating compatibilities and processes that may be needed from project to project (e.g. disease data sharing and analytics agreement and may mean building new communication styles, changing existing processes or creating new ones).

   - Having a win-win for all LHD partners involved in the short run may not be possible but, identifying areas of value and balancing benefits for each partner in the long run can promote and maximize the long run health of the relationships.

15. Get closer, change course, or exit gracefully.
   - There’s no guarantee that LHD partnerships will continue into the future but they are more likely to stay close if partners actively work to achieve incremental successes along the path.

This study focused specifically on the potential use of HIE for chronic disease surveillance and, as evidenced from the dearth of scholarly literature on the subject, presents a chance for LHDs to extract value from HIE data. This lack of relevant literature presents a timely opportunity to explore novel approaches to better collect, analyze, and report on critical areas of growing concern in South Texas such as diabetes and heart disease. However, in the absence of significant evidence in the literature and, more importantly, any substantial real world experiences to reflect on how the use case for HIE and chronic disease surveillance will function operationally, LHD leaders must be prepared to make an ongoing commitment to evaluating and
understanding both anticipated and unanticipated, positive and negative consequences of HIE on LHD operations.

While this plan for change outlines key elements for LHD preparation for HIE and incremental short term wins to build and maintain momentum, the accumulation and achievement of these wins should be placed within the context of a broader organizational and no doubt inter-organizational transformation perspective helping to identify new shared areas of urgency. As Kotter argues many change projects fail because victory is declared too early. Real change runs deep and this statement is especially true with new technology deployment and diffusion where much is unknown.
APPENDIX 1: LOCAL HEALTH DEPARTMENT SURVEY

Health Information Network of South Texas (HINSTX)

Local Public Health Department (LHD) Capacity Assessment

xxxxx, 2013

Introduction
The Health Information Network of South Texas (HINSTX) is a not for profit organization comprised of public, private and nonprofit organizations around the Corpus Christi metropolitan area that is developing and applying health information technologies that will expand access to quality health care and improve health outcomes for people in the service region. The HINSTX seeks to create a health information exchange (HIE) and is building on past health IT initiatives in South Texas and leveraging existing resources to create a foundation for a health information exchange that will assist providers, patients, and public health across the entire care continuum, including the essential connectivity with state and federal HIE initiatives and networks, such as the Texas Health Services Authority (THSA) and the Nationwide Health Information Network (NwHIN). For public health, HINSTX can serve as critical community partner for LHDs and allow for ready access to a diverse swath of the population with a broad set of data cutting across multiple settings.

This assessment tool’s main purpose is to understand local health departments' surveillance capacity to manage the potential new data streams such as staffing, IT support, underlying processes, and others and identify potential gaps that may need to be filled. The results of this will help us in developing recommendations for supporting public health's engagement in the development of HINSTX, state level HIE, and ultimately Nationwide Health Information Network (NwHIN) Direct infrastructure to better serve the need for population level chronic disease monitoring and tracking.

Participation is completely voluntary and there is no penalty for non-participation.

Directions
This is a general survey to provide the HINSTX with information about your organization, current surveillance capacity and how utilizing an HIE could benefit your public health functions and processes. This section can be completed by one or more LHD officials with the necessary information to respond completely.
<table>
<thead>
<tr>
<th>Aim 1</th>
</tr>
</thead>
</table>

### Respondent Information

<table>
<thead>
<tr>
<th>Name of Institution</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent Title/Role</td>
<td></td>
</tr>
</tbody>
</table>

### LHD Profile

<table>
<thead>
<tr>
<th>Total Annual Budget (include federal, state, grants, others)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Annual IT Expenses (FTE, contracts, operations, equipment, others)</td>
<td></td>
</tr>
<tr>
<td>Total Staff (FTE)</td>
<td></td>
</tr>
<tr>
<td>Number of staff with primary responsibilities for epidemiology/surveillance (FTE)</td>
<td></td>
</tr>
<tr>
<td>Number of staff with primary responsibilities for IT (FTE, part-time), if any</td>
<td></td>
</tr>
</tbody>
</table>

### Size of Population Served

### Infrastructure/Connectivity

<table>
<thead>
<tr>
<th>Does the LHD have broadband Internet access?</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the LHD’s top IT priorities?</td>
<td></td>
</tr>
<tr>
<td>Availability of IT equipment (e.g., PCs desktops/laptops, tablets, telecommunications, others) and necessary software for all staff that require it?</td>
<td>3 Highly adequate</td>
</tr>
</tbody>
</table>

### Is the LHD currently directly exchanging electronic data with providers, labs, other partners?

- Who are the partners (providers, state, others)?
- What data is exchanged and how is this currently used?

### Partners:______________________________

### Data exchanged:__________________________

### Data use:________________________________

### Health Registries
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
</table>
| Does the LHD maintain and/or contribute to one or more population health registries? | Check all that apply.  
Asthma  
Cancer  
Diabetes  
Other chronic diseases, list: ____________________ |
| Are there standards for data collection?  
Please describe (data format, structure, semantics, protocols, etc.) | Yes/No  
Briefly  
Describe: ____________________________ |
| **Surveillance**                                                        |        |
| Does the LHD operate or participate in surveillance system(s) designed to monitor chronic diseases?  
If yes,  
• Is this an active, passive, syndromic or other system  
Definitions:  
  o Active- system employing staff members to regularly contact health care providers or the population to seek information about health conditions  
  o Passive- system by which a health department receives reports submitted from hospitals, clinics, public health units, or other sources  
  o Syndromic- active or passive system that uses case definitions that are based entirely on clinical features without any clinical or laboratory diagnosis  
• Number and type of personnel currently involved operating this effort  
• In the past 5 years, has a community-wide representative population-based survey(s) measured the prevalence of some priority chronic health problem (e.g., disability, mental illness, hypertension, diabetes, etc.) and leading risk factors (e.g., smoking, drug use, diet, physical inactivity)  
• Does this system have formal goals, objectives, policies, and procedures? | Yes/No  
1 active; 2 passive; 3 syndromic; 4 other  
Number: ____________________________  
Type: i.e. epi, IT, etc. ____________________________  
Yes—both disease prevalence and risk factors  
Yes—only disease prevalence but not risk factors  
Yes—only risk factors but not disease prevalence  
No—surveys have not assessed any chronic conditions  
No—no population surveys done in past 5 years |
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes/No</th>
<th>Briefly Describe:</th>
<th>Interval, check all relevant.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the LHD have a clearly defined process for system operation?</td>
<td>Yes/No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How are data currently collected (health survey, BRFSS, NHANES,</td>
<td>Yes/No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>administrative data, voluntary reports, other)?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How are the system’s data managed (e.g. transfer, entry, editing,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>storage, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How timely is the data in the current system?</td>
<td></td>
<td>3 Very timely; 2</td>
<td></td>
</tr>
<tr>
<td>How are the system’s data managed (e.g. transfer, entry, editing,</td>
<td></td>
<td>sometimes timely;</td>
<td></td>
</tr>
<tr>
<td>storage, etc.)</td>
<td></td>
<td>1 never timely</td>
<td></td>
</tr>
<tr>
<td>Have core indicators/measures been identified and selected (NCQA, trends,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>etc.)?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are results reported out regularly and, if so, at what interval(s)?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the LHD integrated with national and/or state surveillance systems?</td>
<td>Yes/No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 2 of Meaningful Use guidance for eligible providers has several</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EHR connectivity requirements to public health. Are you able to receive:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immunization information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electronic lab reporting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Syndromic surveillance data</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If no, give timeframe for accomplishing this</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the LHD compliant with national and/or state health information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>exchange guidelines?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Rating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----------------</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Do community health professionals submit reportable disease information in a timely manner to the LHD? | Reportable diseases  
3 Very timely; 2 sometimes timely; 1 never timely  
Chronic disease  
3 Very timely; 2 sometimes timely; 1 never timely; 0 not collected |
| - Timely reports on chronic diseases (if collected)?                      |                 |
| Does the LHD have necessary resources to support health problem and health hazard surveillance and investigation activities? | 3 Highly adequate  
2 Adequate  
1 Present but not adequate  
0 Not adequate at all |
| Does the LHD use information technology (e.g., geographic information systems, mobile applications, word processing, spreadsheets, database analysis, and graphics presentation software) to collect, manage, integrate, and display surveillance data? | 3 Always used  
2 Sometimes used  
1 Never used  
0 Not available |
| Have (or have access to) Masters or Doctoral level epidemiologists and/or statisticians to assess, investigate and analyze public health threats? | 3 Highly adequate  
2 Adequate  
1 Present but not adequate  
0 Not adequate at all |
<p>| Does the LHD maintain written protocols for implementing a program for chronic diseases? | Yes/No |
| What data and capabilities could HIE provide to enable or enhance LHD chronic disease surveillance efforts? | Dissemination |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the LHD provide the general public, policymakers, and public and private stakeholders with information on community health?</td>
<td>Yes/No</td>
</tr>
<tr>
<td>• Community health status (e.g., heart disease rates, cancer rates, environmental risks)?</td>
<td>Yes/No</td>
</tr>
<tr>
<td>• Community health needs, such as those identified by members of the community or through a needs assessment tool including prevention and risk (e.g., obesity, smoking, etc.)?</td>
<td>Yes/No</td>
</tr>
<tr>
<td>Diseases/Conditions Reported:________________</td>
<td></td>
</tr>
<tr>
<td>What is the timeliness of the feedback of surveillance data to the community?</td>
<td>Interval, check all relevant. Monthly Quarterly Biannually Annually Other:_________________________</td>
</tr>
<tr>
<td>Does the LHD plan and conduct chronic disease health education and/or health promotion campaigns?</td>
<td>Yes/No</td>
</tr>
</tbody>
</table>
APPENDIX 2: LOCAL HEALTH DEPARTMENT DIRECTOR INTERVIEW PROTOCOL

Purpose of the Interview

Thank you for taking time out to speak with me today. The purpose of this interview is to understand your perspective on facilitators, barriers, and challenges to participating in a HIE. Findings from this interview will be incorporated into my final dissertation. Do you have any questions or concerns before we get started?

To assist me in keeping up with and for accurate recording, would you mind if I record this interview? Your name will not be used or directly identified in any quotes and all of your responses today will be kept completely confidential unless written consent is requested to attribute a thought or comment to you. Participation is completely voluntary and you may stop the interview at any time with no penalty.

Aims 2 & 3

<table>
<thead>
<tr>
<th>Respondent Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Institution</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Respondent Title/Role</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HINSTX/HIE</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>How familiar are you with HINSTX?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What role if any, have you played in its development and describe your input in the process particularly as it relates to chronic diseases monitoring and tracking?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Why is your LHD interested in HIE? What are the primary benefits you hope will be realized by participation in HIE?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Is the LHD currently participating in any other local HIE?</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes,</td>
</tr>
<tr>
<td>• What is your role?</td>
</tr>
<tr>
<td>• Is the HIE operational and are you able to exchange information?</td>
</tr>
<tr>
<td>o If yes, what is being exchanged?</td>
</tr>
<tr>
<td>What type of information exchange would you</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Question</th>
<th>HIE Potential</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the LHD’s roles and responsibilities in chronic disease surveillance, if any?</td>
<td>• What do you feel should be the LHD’s responsibilities in chronic disease surveillance, if any?</td>
</tr>
<tr>
<td>What are the LHD’s top 3-5 chronic diseases priorities? (Congestive Heart Failure, Diabetes, Coronary Artery Disease, etc.)?</td>
<td></td>
</tr>
<tr>
<td>How effective have past and current chronic disease systems/approaches, if any, been in meeting the needs of community level chronic disease surveillance?</td>
<td>• Why were these surveillance systems/approaches effective or ineffective?</td>
</tr>
<tr>
<td>Given various other priorities and challenges faced by the LHD how much interest is there in initiating work on HIE for chronic disease surveillance?</td>
<td></td>
</tr>
<tr>
<td>How will HIE help achieve health goals in your community?</td>
<td></td>
</tr>
<tr>
<td>In your opinion, how prepared is your health department to fully use HIE for chronic disease surveillance? Describe any resource limitations.</td>
<td></td>
</tr>
<tr>
<td>What are some potential challenges to LHD involvement with a HIE as it relates to chronic disease surveillance?</td>
<td></td>
</tr>
<tr>
<td>What do you feel could be key facilitators in public health engagement with HIEs?</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Answer</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>What are the unique resources that public health could bring to an HIE?</td>
<td></td>
</tr>
<tr>
<td>Would you recommend participation in an HIE to other colleagues? Why or why not?</td>
<td></td>
</tr>
<tr>
<td>Are you familiar with surveillance capabilities and available resources of your LHD peers in the HINSTX service area?</td>
<td></td>
</tr>
<tr>
<td>- If yes, how would you describe the current surveillance capacity and available resources of other LHDs in the area, particularly to participate in an HIE?</td>
<td></td>
</tr>
<tr>
<td>What recommendations would you make to Federal, State, and Local officials to provide greater support and assistance for health IT and HIE initiatives for LHDs?</td>
<td></td>
</tr>
<tr>
<td>Is there anything else you would like to share regarding the LHD engagement with HIE or chronic disease surveillance in general?</td>
<td></td>
</tr>
</tbody>
</table>
REFERENCES


