THE PERCEIVED AND REAL VALUE OF HEALTH INFORMATION EXCHANGE IN PUBLIC HEALTH SURVEILLANCE

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Submitted to the faculty of the University Graduate School in partial fulfillment of the requirements for the degree

Doctor of Philosophy in the School of Informatics,

Indiana University

May 2011

Accepted by the Faculty of Indiana University, in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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Dedication

This dissertation is dedicated to my family – Kathryn, William, and Andrew – as well as my mother – Rebecca – and grandmother – Mary Alice. Their love and support has both inspired and pushed me throughout my academic career.

Acknowledgements

This dissertation required support from a number of individuals. First, I thank my entire research committee for their mentorship and help in refining my ideas, analysis, and writing. I especially thank Julie McGowan, my research mentor, for her guidance and advice on the study design and analysis. I also thank Josette Jones, my committee chair, for her advice and support since beginning the informatics program at IUPUI. Mark Tucker and Ricardo Merriwether from Regenstrief are heartily thanked for their assistance in extracting data from the Indiana Network for Patient Care. I thank Keith Michaelson and Jason Siegel from the Atlas Development Corporation for their assistance in extracting data from the Wisconsin Department of Health Services. Assistance from Shahid Khokhar of Regenstrief with the extraction of all HL7 message data into a format suitable for analysis is greatly appreciated. I thank Tanya Oemig from the Wisconsin Department of Health Services for working with me to secure the Wisconsin data. Finally, I thank all of the men and women who anonymously completed the surveys I sent for their time, honest responses, and feedback on the survey instrument.

ABSTRACT

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Public health agencies protect the health and safety of populations. A key function of public health agencies is surveillance or the ongoing, systematic collection, analysis, interpretation, and dissemination of data about health-related events. Recent public health events, such as the H1N1 outbreak, have triggered increased funding for and attention towards the improvement and sustainability of public health agencies' capacity for surveillance activities. For example, provisions in the final U.S. Centers for Medicare and Medicaid Services (CMS) "meaningful use" criteria ask that physicians and hospitals report surveillance data to public health agencies using electronic laboratory reporting (ELR) and syndromic surveillance functionalities within electronic health record (EHR) systems. Health information exchange (HIE), organized exchange of clinical and financial health data among a network of trusted entities, may be a path towards achieving meaningful use and enhancing the nation's public health surveillance infrastructure. Yet the evidence on the value of HIE, especially in the context of public health surveillance, is sparse.

In this research, the value of HIE to the process of public health surveillance is explored. Specifically, the study describes the real and perceived completeness and usefulness of HIE in public health surveillance activities. To explore the real value of HIE, the study examined ELR data from two states, comparing raw, unedited data sent from hospitals and laboratories to data enhanced by an HIE. To explore the perceived value of HIE, the study examined public health, infection control, and HIE professionals' perceptions of public health surveillance data and information flows, comparing traditional flows to HIE-enabled ones. Together these methods, along with the existing literature, triangulate the value that HIE does and can provide public health surveillance

processes. The study further describes remaining gaps that future research and development projects should explore.

The data collected in the study show that public health surveillance activities vary dramatically, encompassing a wide range of paper and electronic methods for receiving and analyzing population health trends. Few public health agencies currently utilize HIE-enabled processes for performing surveillance activities, relying instead on direct reporting of information from hospitals, physicians, and laboratories. Generally HIE is perceived well among public health and infection control professionals, and many of these professionals feel that HIE can improve surveillance methods and population health. Human and financial resource constraints prevent additional public health agencies from participating in burgeoning HIE initiatives. For those agencies that do participate, real value is being added by HIEs. Specifically, HIEs are improving the completeness and semantic interoperability of ELR messages sent from clinical information systems. New investments, policies, and approaches will be necessary to increase public health utilization of HIEs while improving HIEs' capacity to deliver greater value to public health surveillance processes.

Josette F. Jones, Ph.D., Chair

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List of Abbreviations

APIC Association for Professionals in Infection Control and Epidemiology

ARRA American Recovery and Reinvestment Act of 2009

CDC U.S. Centers for Disease Control and Prevention

EHR Electronic Health Record

ELR Electronic Laboratory Reporting

HIE Health Information Exchange

HL7 Health Level Seven, Inc.

IC Infection Control

ICP Infection Control Preventionist (or Professional)

INPC Indiana Network for Patient Care

ISDH Indiana State Department of Health

LHD Local Health Department

LIMS Laboratory Information Management Systems

LOINC Logical Observation Identifiers Names and Codes

NCD Notifiable Condition Detector

NwHIN Nationwide Health Information Network

ONC Office of the National Coordinator for Health Information Technology

PH Public Health

SHA State Health Agency

SNOMED CT Systematized Nomenclature of Medicine-Clinical Terms

WDHS Wisconsin Department of Health Services

Introduction

Protecting the health and safety of populations is the challenge conferred by society onto public health agencies. The work of public health agencies includes the prevention of, detection of, and response to both natural (e.g., chronic disease, disease outbreak, environmental) and man-made (e.g., biological warfare, bioterrorism) health-related events. The threats posed by disease, environmental harms, and bioterrorism are highlighted by recent events, including the pandemic of H1N1 influenza (CDC, 2009a), the rise in state smoke-free indoor air laws (CDC, 2009c), Hurricane Katrina (CDC, 2005b), and the deadly anthrax attack (Federal Bureau of Investigation, 2008). These events serve as a reminder that public health agencies are always there, often working in the background, to prepare for and respond to such population-level events that threaten the health and safety of individuals and populations.

Recent public health events have also triggered increased funding for and attention towards the improvement and sustainability of public health agencies' capacity for surveillance (Bravata et al., 2004; CDC, 2008b). Public health surveillance is "the ongoing, systematic collection, analysis, interpretation, and dissemination of data about a health-related event for use in public health action to reduce morbidity and mortality and to improve health" (J. W. Buehler, Hopkins, Overhage, Sosin, & Tong, 2004; German et al., 2001). Restated, public health surveillance involves the gathering and use of data to plan for, monitor, and intervene in situations where natural or man-made health events threaten individuals or populations. This requires public health agencies to collect, analyze, and interpret health event data and trends. Public health agencies must coordinate responses to threats with other public health and government agencies as well as health care providers. The information and knowledge generated from public health surveillance is shared with researchers, other public health agencies, health care providers, and the general public (CDC, 2009b).

Surveillance often centers on the use of syndrome-based case definitions (J.W. Buehler, Berkelman, Hartley, & Peters, 2004 Jul). These case definitions are typically defined by national or international committees and then tracked using laboratory

confirmations or health system records. Figures are reported monthly, quarterly, or annually to entities such as the CDC or the World Health Organization. To monitor the eradication of poliomyelitis, for example, the Pan American Health Organization (PAHO) established an independent International Commission for the Certification of Poliomyelitis Eradication in the Americas (ICCPE). This commission determined criteria for certifying a region as polio-free, and one of these criteria was surveillance for acute flaccid paralysis cases. Through surveillance and successful vaccination campaigns, the poliovirus was certified as eradicated in the Americas in 1994 (CDC, 1994).

Public health agencies gather surveillance data from a variety of disparate sources. The most common sources of surveillance data are medical providers and laboratories (Doyle, Glynn, & Groseclose, 2002; Lombardo & Buckeridge, 2007), which are often required by state law to report notifiable diseases (Doyle et al., 2002; Silk & Berkelman, 2005). Notifiable diseases are those for which "regular, frequent, and timely information regarding individual cases is considered necessary for the prevention and control of the disease." (McNabb et al., 2008) Conventional methods for reporting notifiable diseases include the telephone, facsimile, and postal mail (Effler et al., 1999). These manual, spontaneous reporting processes have been shown to be incomplete and untimely (Doyle et al., 2002; Jajosky & Groseclose, 2004; Overhage, Grannis, & McDonald, 2008; Silk & Berkelman, 2005). Incomplete and untimely processes can delay public health officials' response to emerging public health threats, which puts the health of individuals and communities at risk.

Advances in health information technologies, including but not limited to electronic health record and laboratory information systems, have shifted efforts in public health agencies towards greater use of information systems and networks to automate disease reporting and surveillance (Doyle et al., 2002; Lombardo & Buckeridge, 2007). Two important areas of development and research within the spectrum of automated surveillance activities are electronic laboratory reporting (ELR) and syndromic surveillance. ELR is the submission of laboratory data, following the confirmation of a notifiable disease, to public health agencies. Syndromic surveillance, on the other hand,

detects initial manifestations of disease before diagnoses (clinical or laboratory) are established (J. W. Buehler et al., 2009; Lazarus, Kleinman, Dashevsky, DeMaria, & Platt, 2001; Lober et al., 2002). Both ELR and syndromic surveillance have been shown to improve the process of detecting public health events in order to more quickly initiate a public health response, leading to reduced impacts on the health and safety of individuals and populations (J. W. Buehler et al., 2004; Doyle et al., 2002; Effler et al., 1999; Kleinman & Abrams, 2008).

ELR and syndromic surveillance involve the exchange of data between health care providers, laboratories, and public health agencies. This exchange is more broadly referred to in the health informatics field as health information exchange or HIE (Dixon, Zafar, & Overhage, 2010). HIE can be facilitated by a third party organization that provides local leadership, oversight, fiduciary responsibility, and governance for the development, implementation, and application of secure exchange of data across many care settings (Overhage, Evans, & Marchibroda, 2005), including but not limited to hospitals, ambulatory centers, laboratories, and payers (Biondich & Grannis, 2004).

HIEs often have access to a wide range of data on a diverse population across health care settings. HIEs involve a mix of health care organizations, many of which are otherwise competitors in the local health care marketplace (Dixon & Scamurra, 2007). These organizations are typically spread across a geographic region that causes them to be labeled as community-wide or statewide (AHRQ, 2009a). Given their geographic coverage, HIEs usually possess large amounts of data on populations served by one or more public health agencies. HIEs therefore have the potential to provide valuable information that can be utilized to detect public health threats and provide pathways for communication with medical providers.

Although conceptually a partnership between public health and HIE organizations seems logical, few public health agencies today are active HIE partners. Several well known HIEs, such as the Indiana Network for Patient Care and the Delaware Health Information Network, do involve public health agencies as key partners (DHIN, 2008;

Overhage, 2008). Similar levels of participation in HIE activities in other communities, however, is limited. A recent report from Hessler, Soper, Bondy, Hanes, & Davidson (2009) shows that few public health agencies exchange data with an HIE organization. The peer-reviewed literature similarly reflects a lack of evidence indicating participation in HIE activities by public health agencies. A query in MEDLINE on December 31, 2009, of the indexed and non-indexed literature for "public health" and "health information exchange," for example, yielded only 20 references.

The lack of evidence extends to the benefits of public health agency participation in a HIE organization. Although attractive as partners, it is often challenging for HIEs to engage public health agencies and vice-versa. Hessler et al. (2009) examined perceptions of public health involvement in HIE and found that public health agencies reported a number of challenges, including funding, insufficient technology (possessed by the local health department), and skepticism regarding the benefits to public health participation. The skepticism may be due, in part, to the fact that very few public health use cases, like surveillance, have been formally evaluated and reported in the literature (Shapiro, 2007). There are also legal and policy barriers to public health involvement in HIEs, including variation in agency business practices and state laws that govern the exchange of confidential, protected health information (Dimitropoulos, 2007).

The recently passed American Recovery and Reinvestment Act of 2009 (ARRA) appropriated approximately \$40 billion for new investments in health information technology (health IT) during the next several fiscal years. Much of this investment is for the adoption and use of electronic health record systems in doctors' offices and the development and expansion of health information exchange (HIE) organizations in communities across the U.S. (HIMSS, 2009). In the final rule adopted by HHS in July 2010, hospitals and physicians which seek to qualify for Medicare and Medicaid EHR incentive payments must achieve certain criteria outlined in the rule. There are core criteria that all hospitals or physicians must achieve, and there are "menu set" criteria from which hospitals and physicians must achieve some subset of items on the menu (CMS, 2010a). Several core criteria require electronic exchange of clinical information,

and several menu set items contain criteria that involve electronic submission of surveillance data to public health agencies. This has boosted interest in HIEs, ELR for notifiable conditions, and syndromic surveillance among hospitals, physicians, public health agencies, and the public.

A lack of evidence on the benefits of HIE for public health surveillance and low adoption of HIE among public health agencies provided an opportunity to study this area of health informatics. ELR and syndromic surveillance have been shown to improve public health surveillance (Effler et al., 1999; Overhage et al., 2008; Panackal et al., 2002; Silk & Berkelman, 2005). HIEs and HIE support for ELR and syndromic surveillance, however, are not well understood. Therefore this study collected and examined data on the use and perception of HIEs by public health agencies and providers who are responsible for reporting data to public health agencies. On the following pages, a study that examined the real and perceived benefits of HIE to public health surveillance is described. In the Background section, a more thorough review of public health surveillance, ELR, syndromic surveillance, and HIE is presented. The Methods section describes the methods used to collect and examine data from public health agencies, health care provider organizations, and HIEs. The Results section summarizes the findings from the study. The Discussion section describes the findings, puts them in context with previous studies and current national public health surveillance initiatives, and makes recommendations for data producers (health care provider organizations), intermediaries (HIEs), and data receivers (public health agencies). The Conclusion section summarizes the study's findings and suggests a path forward for HIEs and public health agencies.

Background

The work performed by public health agencies is diverse and expansive in nature. The Institute of Medicine definition (IOM, 1988), used widely in the literature and U.S. Government reports, describes three core functions of public health: 1) assessment and monitoring of the health of communities and populations at risk to identify health problems and priorities; 2) formation of public policies to solve identified local and national health problems and priorities; and 3) assurance that all populations have access to appropriate and cost-effective care, including health promotion and disease prevention services, and evaluation of the effectiveness of that care. Other frameworks and operational definitions exist for classifying the work of public health agencies, most notably those from the CDC's Office of the Chief of Public Health Practice (CDC, 2008a), the Minnesota Department of Health (2001), and the National Association of County and City Health Officials (2005). The Public Health Informatics Institute (PHII, 2006) provides a cross-walk that aligns the various frameworks into a singular model of public health practice.

The act of collecting, analyzing, interpreting, and disseminating data and information about a public health event is more commonly referred to as public health surveillance (J. W. Buehler et al., 2004). Effective surveillance requires "timely, accurate, and complete data" (Lombardo & Buckeridge, 2007, p. 266). Surveillance data and information enables public health policy development and communication to providers and individuals about what steps they should take to protect health and safety – outbreak management. The data and information further enable public health officials to plan for future outbreaks and disasters – also known as public health preparedness (Braun et al., 2006).

Public health surveillance began in 1854 when John Snow used reported mortality data and location information to convince authorities to remove a water pump that was the source of a cholera outbreak (Lombardo & Buckeridge, 2007). National requirements for public health reporting were introduced in the United States in 1878

(Lombardo & Buckeridge, 2007). Cholera, smallpox, plague, and yellow fever were the first infectious diseases to be collected by the U.S. Marine Hospital Service.

Public health surveillance activities, and public health reporting requirements aimed at supporting the capture of timely, accurate, and complete data necessary for those activities, evolved little during their first 122 years. Although highly variable and based on state law (Roush, Birkhead, Koo, Cobb, & Fleming, 1999), public health reporting laws generally specify a list of notifiable conditions and associated data elements that physicians and laboratories are required to report to public health agencies. In 1902, the U.S. Surgeon General introduced standards for the collection, compilation, and distribution of data at the local, state, and national levels (Lombardo & Buckeridge, 2007). Then in 1961 the CDC assumed the duties of standardization from the Surgeon General (Lombardo & Buckeridge, 2007) and formalized them within a new initiative called the National Notifiable Diseases Surveillance System (NNDSS). Although responsible for establishing standards for the collection, compilation, and distribution of surveillance data, the CDC does not have the statutory authority to require states to report surveillance data to the Agency. It remains the duty of the states to individually collect, compile, and distribute surveillance data.

At the beginning of the twenty-first century, the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services (HHS), in consultation with the CDC, commissioned a report "to improve the nation's core capacity for infectious diseases surveillance." (Baxter et al., 2000, p. 1) The team that authored the report reviewed the literature on surveillance best practices and interviewed over 50 stakeholders involved in surveillance activities. The report concluded that public health surveillance capacity in the U.S. was "a product of a century of piecemeal investments as the country has organized to respond to various biological threats." (Baxter et al., 2000, p. 2) Categorical funding had resulted in uneven development of the nation's surveillance infrastructure, which left significant gaps (Table 1) that made the U.S. vulnerable to growing threats from natural and man-made events.

There were no clear set of standards that defined the critical surveillance needs and associated capacity requirements at all levels (local, state, federal) of the public health infrastructure.

Staffing, skill levels, technological capability, and training were uneven across the country, leaving some populations less well protected from infectious disease threats than others.

Staff capacity at the state and local levels was frequently inadequate to support ongoing analysis of surveillance data to detect changes in the epidemiology of infection, to evaluate surveillance efforts, to plan interventions, and to set priorities.

A lack of data standards and issues of privacy, confidentiality, and security prevented the various levels of public health from sharing surveillance data.

Computerized decision and analytic support tools had not been developed to their potential to support infectious diseases surveillance activities.

Public health laboratories lagged behind the private sector in terms of technology.

Surveillance systems were too dependent on the case report to trigger a public health response. There was also a lack of system infrastructure to facilitate reporting from providers to public health agencies.

Large volumes of data flowed through the public health infrastructure but feedback and analysis needed to be more effectively packaged and disseminated from the CDC to state and local public health officials, from state to local public health officials, and from public health agencies to health care providers.

Public health and clinical education too was found to be weak regarding surveillance. Programs did not produce highly skilled public health workers, and clinical education did not stress the importance of public health surveillance.

Public health did not effectively communicate the value and role of surveillance to policymakers or the media.

As a result of categorical funding, surveillance activities tended to focus on specific diseases rather than on a broad range of threats. Capacity was uneven across disease areas and there seemed to be no core infrastructure available in many public health agencies.

Table 1 – Gaps in Public Health Surveillance as Described in Baxter et al. (2000)

In addition to outlining the results of the literature review and interviews, the report by Baxter, et al. (2000), presented a 5-year investment plan aimed at closing the identified public health surveillance infrastructure gaps. The proposed funding was to provide core support for surveillance activities through grants to academic, laboratory, and public health organizations. Information technology, including hardware, software,

analytic, and decision support functionality, was a common theme in the recommended funding strategy. The role of information technology in public health surveillance was also a theme in other reports and discussions taking place at the end of the twentieth century (Davis & Lederberg, 2000; Lober et al., 2002).

Significant investment and development of the nation's public health surveillance capacity occurred following the release of the reports at the turn of the century from Baxter et al. (2000), Davis & Lederberg (2000), and the U.S. Government Accountability Office (GAO, 1999). CDC's Fiscal Year (FY) 2000 Congressional Appropriation for bioterrorism, the CDC budget line item which best approximates spending on surveillance, was \$123.6 million (CDC, 2005a). This amount grew by a factor of 10 to \$1.57 billion by FY 2005 (CDC, 2005a) where it has remained relatively constant. For FY 2010, the appropriated amount was \$1.55 billion (CDC, 2010b). The U.S. Agency for Healthcare Research and Quality (AHRQ) also received funding to examine surveillance and preparedness with an emphasis on bioterrorism (AHRQ, 2002). Much of this spending was invested in advanced IT systems and networks that aimed to link providers and public health agencies together to better detect and cooperatively address disease outbreaks (AHRQ, 2002; GAO, 2004). Two key areas within the spectrum of public health surveillance activities that received a significant proportion of these investments were electronic laboratory reporting and syndromic surveillance.

Electronic Laboratory Reporting

Electronic laboratory reporting (ELR) describes the electronic transmission of laboratory data, following the confirmation of a notifiable disease, to a public health agency. ELR has been used successfully in a number of cities, states, and nations to improve public health surveillance (Effler et al., 1999; Nguyen, Thorpe, Makki, & Mostashari, 2007; Overhage et al., 2008). Public health agencies that have implemented and used ELR report a number of benefits. First, notifiable disease reports that arrive electronically arrive faster than previously used paper-based reports (Effler et al., 1999; Overhage et al., 2008; Panackal et al., 2002). Timeliness increases the capability of the public health agency to respond to an emergent threat quickly.

Second, ELR has been shown to increase completeness or the proportion of notifiable disease reports that are reported to public health (Effler et al., 1999; Nguyen et al., 2007; Overhage et al., 2008; Panackal et al., 2002). Thus ELR addresses the well known problem of underreporting of notifiable disease cases (Doyle et al., 2002; Lombardo & Buckeridge, 2007).

Despite important benefits, ELR has several challenges. For example, Rushworth, Bell, Rubin, Hunter, & Ferson (1991) found that while a new ELR system was successful in delivering up to 80 percent of notifiable disease reports in the community nearly a full week before clinicians reported those cases to public health officials, the reports failed to include such details about the cases including the date of disease onset, the provider's name and address, and the patient's name and address (Vogt, 1996). Incomplete reports that lack key information necessary for public health professionals to investigate new cases of notifiable disease has been confirmed in a number of subsequent evaluations of ELR (M'ikanatha, Southwell, & Lautenbach, 2003; Nguyen et al., 2007; Overhage et al., 2008; Panackal et al., 2002; Wurtz & Cameron, 2005), and it has been placed on an outstanding issues list for resolution as ELR and laboratory information management systems (LIMS) systems mature (Abellera, 2009).

Data standards are also key barriers to more effective use of ELR. In 1999, the CDC and other important voices in public health called for the development of an unified approach to ELR (CDC, 1999). The result of discussions at the CDC meeting and afterward culminated in the adoption of the messaging standard Health Level 7 (HL7) and data vocabularies Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT) and Logical Observation Identifiers, Names, and Codes (LOINC) for ELR transaction between laboratories and public health (Overhage, Suico, & McDonald, 2001; White, Kolar, & Steindel, 1999). Despite several implementations of ELR in local and state health departments, laboratories continue to identify test procedures and results using proprietary codes instead of the data standards LOINC and SNOMED CT (M'ikanatha et al., 2003; Overhage et al., 2001; Vreeman, Stark, Tomashefski, Phillips, & Dexter, 2008; Wurtz & Cameron, 2005). Local vocabularies limit the immediate use of machine

computable processes for identifying and interpreting new test and result codes, which impacts the ability of systems that receive ELR data from responding quickly in emergent public health situations. A sample HL7 formatted ELR message with standardized LOINC and SNOMED CT codes is provided in Figure 1. In the sample message, the lab test is identified as LOINC code 44089-1 (a culture for *Escherichia coli*) and the result is identified as SNOMED CT concept L-15611 (*Escherichia coli*), which suggests a positive result for *E. coli*.

```
MSH|^~\&|CHAMELEON|XYZ State Laboratory
^52D0669558^CLIA|vCMR|PHESS|20081105120021||ORU^R01|7551:324329:117|T|2.3
PID|1||<MASKED>||<MASKED>||<MASKED>^<MASKED>^<MASKED>^<MASKED>^<MASKED>
KED>^^^<MASKED>|||
ORC|CN|08BC005783|08BC005783^XYZ State Laboratory
^52D0669558^CLIA||||||||ANYWHERE HEALTH
DEPARTMENT | 9202628090 | | | | | | | | ANYWHERE HEALTH DEPARTMENT | 123 E MAIN ST
OBR|1|08BC005783|08BC005783^XYZ State Laboratory
^52D0669558^CLIA|^^^610E:116^ESCHERICHIA COLI 0157:H7 ONLY
CULTURE: ^L|||<MASKED>|||||||<MASKED>| ^^STOOL||9202628090|||||200811040000
00||F
OBX|1|CE|44089-1^E coli O157H7 XXX Cult^LN^610E:116^ESCHERICHIA COLI
O157:H7 ONLY CULTURE: ^L|1|L-15611 Escherichia coli, serotype
0157:H7^SNM\escherichia coli serotype 0157:H7^Escherichia coli serotype
0157:H7^L|||A|||F|||<MASKED>
NTE | 1 | | THIS ISOLATE IS 0157 POSITIVE BY SLIDE AGGLUTINATION.
FTS||End of File
```

Figure 1 - Sample HL7 Message

ELR can also significantly impact public health workflow. In New Jersey, for example, the introduction of ELR led to a significant increase in the number of "investigation pending" notifiable disease reports (McHugh, Sorhage, Tan, & Langer, 2008). Additional cases reported increased the completeness of Lyme disease reports submitted to the local health department, but it "exceeded local investigative capacity." The additional burden on public health personnel responsible for processing the pending reports detracted from other public health duties, increased costs associated with the system, and necessitated personnel changes. Florida anticipated similar challenges for salmonella, shigellosis, and hepatitis A for its introduction of ELR into surveillance activities (Kite-Powell, Hamilton, Hopkins, & DePasquale, 2008).

Overhage et al. (2001) note that sending laboratories often neglect to properly set the abnormal flag in the HL7 message, which limits the ability of public health to filter out results those in the normal range and decrease the size of the epidemiologist's inbox. Overhage et al. (2008) also suggest that additional data from the electronic medical record, such as a concomitant liver function test elevation, could be used to limit the number of pending tests in the queue for health department personnel to review and process. Other methods suggested for better supporting public health workflow include LIMS rules to flag an ELR as positive (Wurtz & Cameron, 2005) and natural language processing (NLP) to improve surveillance system recognition of positive results once they have arrived from the LIMS (Friedlin, Grannis, & Overhage, 2008).

Syndromic Surveillance

Syndromic surveillance detects initial manifestations of disease before diagnoses (clinical or laboratory) are established (J. W. Buehler et al., 2009; Lazarus et al., 2001; Lober et al., 2002). Data and information in syndromic surveillance systems come from a variety of sources, including hospital emergency department visits, ambulatory clinic visits, school absenteeism, poison control centers, and over-the-counter medication sales (Lombardo & Buckeridge, 2007). These systems further employ a variety of algorithms and methods to examine surveillance data and determine aberrations for alerting public health officials.

Syndromic surveillance systems are in use within many public health jurisdictions in the U.S. and abroad. According to a survey conducted by the International Society for Disease Surveillance, around 80 percent of state and territorial health departments in the U.S. performed some form of syndromic surveillance as of 2007-2008 (James W. Buehler, Sonricker, Paladini, Soper, & Mostashari, 2008). Nearly all of the agencies responding to the survey also indicated plans to adopt or expand syndromic surveillance activities in the next two years. Evidence of growing adoption and use of syndromic surveillance has also been reported worldwide. The United Kingdom (Doroshenko et al., 2005), Armenia (Wuhib, Chorba, Davidiants, Mac Kenzie, & McNabb, 2002), Taiwan (Wu et al., 2008), and New Zealand (Jones & Marshall, 2004) are among those nations whose

ministries of health have implemented syndromic surveillance systems in recent years. May and colleagues (2009) further discuss the potential implementation and use of surveillance systems in developing nations going forward.

Evidence demonstrating the benefits of syndromic surveillance has steadily grown in the last decade. Between 1985 and 2002, there was a dearth of evidence that syndromic surveillance provided any benefit beyond traditional surveillance methods (Bravata et al., 2004). Given this paucity of evidence, the CDC and other public health informatics stakeholders called for and developed frameworks to support their evaluation following implementation (J. W. Buehler et al., 2004; Dausey et al., 2005; Lober et al., 2002). Today evidence from the syndromic surveillance systems developed in the late 1990s and 2000s is now appearing in the scientific literature. Loveridge et al. (2010) report that monitoring phone calls into a National Health Service (NHS) hotline for chief complaints of vomiting can provide a four week early warning signal of an impending, seasonal norovirus outbreak. Griffin et al. (2009) find that emergency department chief complaint data can provide an early signal, ranging from two days to two weeks, for seasonal influenza.

Syndromic surveillance, like ELR, possesses several challenges for public health agencies. A primary challenge for public health agencies is coordination and integration of syndromic surveillance systems. Surveillance initiatives over the past twenty years have produced many independent electronic systems designed to collect, analyze, interpret, and disseminate information to public health officials. A report by the U.S. Government Accounting Office describes 19 surveillance systems as of 2004 in use at the state and federal levels (GAO, 2004). These systems have a need to talk with one another (Lombardo & Buckeridge, 2007), either to exchange information between levels of government or integrate multiple syndromic indicators into a single "view" of a community or region. These systems, however, do not all use a single messaging platform that enables easy integration, and data standards that enable semantic interoperability remain a challenge. The CDC Public Health Information Network (PHIN) initiative has defined standards for interoperable communication between systems

(CDC, 2010a). The CDC is further exploring the use of the Nationwide Health Information Network (NwHIN) and Health Information Technology Standard Panel's Biosurveillance Use Case and associated transaction and content standards (Population Perspective Technical Committee, 2008).

A secondary challenge for syndromic surveillance systems is the development of better methods for analyzing syndromic indicators. Acceptable levels of sensitivity and specificity are important, yet not all reports on syndromic surveillance systems report these outcomes (Bravata et al., 2004). Weak sensitivity and specificity can increase "noise" or false (negative and positive) reports, which negatively impacts public health's investigative capacity. Various systems employ different methods for analyzing syndromic data, and there is controversy about the best methods for both analysis and dissemination to public health officials (Bravata et al., 2004; Lombardo & Buckeridge, 2007). Future systems will not only need to standardize communication and data elements but also the methods used to analyze the increasing number of data feeds and elements captured by various sources.

Health Information Exchange

Health information exchange (HIE) is the sharing of clinical and administrative health care data among health care institutions, providers, and data repositories (AHRQ, 2009b). ELR and syndromic surveillance systems are examples of HIE in its broadest sense, because they involve exchange of clinical and administrative data between providers, laboratories, pharmacies, and public health agencies. However, the term HIE is most often associated with organized groups of health care data producers and consumers, many of whom are health care marketplace competitors, who routinely exchange data to achieve a common purpose or aim (Dixon & Scamurra, 2007). Examples of organized HIEs include the Indiana Network for Patient Care (Biondich & Grannis, 2004), the Massachusetts eHealth Collaborative (Rudin, Simon, Volk, Tripathi, & Bates, 2009), and the MidSouth eHealth Alliance (K. B. Johnson et al., 2008). Currently there are an estimated 193 initiatives across the U.S. pursuing HIE activities (eHealth Initiative, 2009). Additional initiatives are anticipated given congressional authorization

for categorical funding to establish statewide HIE networks in all U.S. states and territories ("The American Recovery and Reinvestment Act of 2009," 2009).

The evidence base for HIE is similar to the public health surveillance evidence base in that few published studies and general methods for evaluation are available for broad use (Hripcsak et al., 2007). Generally HIE is considered to benefit a range of participant types (e.g., providers, payers, public health agencies) and promises to improve health care quality, safety, and efficiency (Chaudhry et al., 2006; Congressional Budget Office, 2008; Dixon, 2007; K. B. Johnson & Gadd, 2007; Shapiro et al., 2006; Walker et al., 2005). Recent legislation, developed with the assumption of these benefits, funds the expansion of statewide and regional HIEs across the U.S., and it requires greater use of HIE to improve public health surveillance (CMS, 2010b; HIMSS, 2009). Furthermore, the CDC plans to fund additional work in the use of HIE to improve public health surveillance (CDC, 2010b).

Despite models for evaluating HIE when used to improve public health activities (Shapiro, 2007), there exist few published evaluation studies in this area. For example, a query in MEDLINE on December 31, 2009, for "public health" and "health information exchange" yielded only 20 references. Most of these references simply describe the potential benefit of HIE in a public health context. One study, however, did compare HIE-enhanced emergency department visit surveillance to an existing, manual reporting method (Shapiro, Genes, Kuperman, Chason, & Richardson, 2010). That study found that when emergency departments experience dramatic increases in utilization, such as during the H1N1 pandemic of 2009, HIE-enhanced surveillance reports continue to stream in at a steady rate as opposed to manual reporting rates which fluctuate based on workload in the emergency department. Such evaluation of HIE-enhanced public health surveillance is important, but the evidence base overall remains weak.

Given a weak evidence base, it is not surprising that few public health agencies currently participate in organized HIE initiatives. Researchers surveyed HIEs and public health agencies in early 2007 about their perceptions of HIE (Hessler et al., 2009). The researchers found that just over a third (35 percent) of the HIE respondents indicated

that public health agencies participated in the exchange activities. Forty percent of public health agency respondents indicated participation in an HIE. The study further described challenges that public health agency participants reported, including lack of funding, insufficient technology (possessed by the local health department), and skepticism regarding the benefits to public health participation.

Synthesizing the existing evidence suggests that a) while electronic reporting of notifiable disease and syndromic data to public health can improve timeliness of information delivered to public health agencies as well as the completeness of disease incidence reporting, there are many practical challenges facing agencies who desire to receive direct feeds of electronic data from clinical information systems; b) although many look to HIEs for support and enhancement of electronic surveillance processes, few health agencies are actively exchanging data with HIEs; c) some public health agencies are skeptical of the claims that HIEs can enhance public health surveillance; and d) there is virtually no data to support or refute the claims that HIEs add value to public health surveillance processes. The synthesis led the researcher to develop a study to explore the value that HIEs can and do bring to public health surveillance processes. This study specifically seeks to examine the value added by HIEs to the completeness, timeliness, and usefulness of clinical data exchanged in support of public health surveillance processes. The study builds on the existing evidence from prior research on ELR, syndromic surveillance, and HIEs while addressing research gaps. The study further explores the topic of HIE value following significant investment from the CDC and U.S. Office of the National Coordinator for Health Information Technology (ONC) to improve public health surveillance using health information technologies, including EHRs and HIEs. This makes the study a timely, practical examination that can inform both public health policy and HIE development. It will further provide much needed data for the evidence base with respect to the value of HIEs and their ability to enhance public health surveillance.

Methods

To evaluate the real and perceived benefits of HIEs to public health surveillance, the study used a mixed methods approach (R. B. Johnson & Onwuegbuzie, 2004). In other words, a combination of quantitative and qualitative methods were utilized to examine the benefits that HIE has brought and can bring to the processes involved in public health surveillance. This approach was chosen to enable triangulation, or the convergence and corroboration of results from different methods and designs studying the same phenomenon (R. B. Johnson & Onwuegbuzie, 2004; Patten, 2005), of the methods and data. Triangulation was desired to synthesize and compare the objective data collected from clinical information systems and the subjective data captured from individuals working in public health agencies, hospitals, and HIEs. All methods and analysis focused on capturing the real benefits of HIEs, benefits experienced by those involved in public health surveillance processes, as well as the perceived benefits of HIEs, benefits those involved in public health surveillance processes believe will come from the inclusion of HIEs in public health surveillance activities.

The "Framework for Evaluating Public Health Surveillance Systems for Early Detection of Outbreaks" (J. W. Buehler et al., 2004) from the CDC guided the study's overall approach and areas of focus. At its core, the framework describes three aspects of a given public health surveillance system: System Description, Outbreak Detection, and System Experience. The System Description aspect fully describes the system, which includes the intended purpose, how the system should be used, stakeholders who use the information, stakeholders who input data into the system, and the operations of the system. Outbreak Detection focuses on how the system captures data, data processing, health event signal detection, and the initiation of public health investigation. This section further describes the validity of the system in terms of specificity and sensitivity as well as the quality of the data and information in the system. The final section is titled System Experience and outlines current users of the system, the ability of the system to be adaptable over time, the portability of the system as well as the general costs associated with implementation and adoption.

Time limitations placed on this study prohibited primary data collection within each section and sub-section of the framework. Therefore the data and information captured and analyzed in this study were prioritized based on two criteria: a) lack of availability in the existing evidence-base and b) importance to public health practice. Although there is little evidence at the intersection of public health and HIE, there is a significant and growing body of evidence in each domain. This literature, primarily knowledge from previous HIE evaluation studies, is sufficient for answering many sections in the framework. Existing knowledge on HIEs and how they work, for example, could be applied to explain the intended purpose of HIE as a surveillance "system," the stakeholders involved in HIE, and HIE system operation.

Completeness, timeliness, and usefulness are paramount and under-measured areas of the CDC framework (Bravata et al., 2004; J. W. Buehler et al., 2004; J. W. Buehler et al., 2009). Furthermore, given a central focus by HIEs on the exchange of clinical data, the study focused on examining the completeness, timeliness, and usefulness of the data used in public health surveillance processes. Data from HIEs are hypothesized to be more complete, timely, and useful than the data received from other sources used in public health surveillance processes.

The study involved two distinct research strategies to explore the completeness, timeliness, and usefulness of public health surveillance data submitted through an HIE. First, real-world electronic laboratory reporting messages, extracted from public health and HIE information systems, were analyzed and compared to assess the completeness and usefulness of the data in the messages. Second, a survey was distributed to public health agencies, health care provider organizations, and HIEs to measure attitudes and perceptions regarding a) the experiences of infection control professionals with HIE-supported processes for capturing and reporting surveillance data to public health agencies; b) the relationships between public health agencies and HIE; c) the experiences of public health professionals in using HIE-provided data; and d) the completeness, timeliness, and usefulness of HIE-enhanced data used in public health surveillance activities.

The Institutional Review Board at Indiana University-Purdue University Indianapolis (IUPUI) reviewed and approved both research strategies (Study Numbers 1005-68 and EX1010-24). The first research strategy was also reviewed and approved by the Research Committee of the Indiana Network for Patient Care (INPC) as well as the Data Review Board of the Wisconsin Department of Health Services (WDHS).

Real-World, HIE-Enhanced Public Health Surveillance Data

Health Level 7 (HL7) messages from two states in the U.S. form the basis for this component of the study. Specifically, the study examined messages which contained data on potentially notifiable conditions for reporting to public health agencies (e.g., ELR messages). These messages were collected from laboratories, hospitals, and HIEs serving parts of Indiana and Wisconsin.

Public health departments can receive ELR messages via two methods. Some laboratories and hospitals provide public health agencies with direct, outbound HL7 feeds of data, which requires the health department to aggregate, process, and summarize the raw data. Other public health departments use an HIE to aggregate and pre-process the data and receive only a single feed (or minimal number of feeds) for surveillance data. This study examined and compared these methods of data capture using raw versus pre-processed HL7 data. The analysis was aided by the fact that the sources of the data (Regenstrief Institute for Indiana data and Atlas Public Health for the Wisconsin data) keep copies of both the raw and processed HL7 messages. The comparison will examine the value that HIEs add by acting as a central gateway or processing center for ELR data.

The HL7 messages were extracted from the production servers housed at the Regenstrief Institute and the Wisconsin Department of Health Services. The messages from Regenstrief originated from the incoming, pre-processed, and outbound queues associated with the Regenstrief Notifiable Condition Detector (NCD). The NCD critically examines HL7 messages from the Indiana Network for Patient Care (INPC), an HIE serving multiple parts of Indiana, that potentially contain information on reportable results. Messages determined to be reportable are reported to the Indiana State

Department of Health (ISDH) on behalf of the INPC and its member institutions (e.g., hospitals, labs, physician practices). The INPC receives between 500,000-1,000,000 HL7 messages per day from a growing number of hospitals, laboratories, physician practices, radiology centers, payers, and other health care organizations. The full HL7 messages from the NCD queues (with all original data intact) were copied from the queues to another secure server within Regenstrief for analysis.

The messages from WDHS, Wisconsin's state public health agency, were extracted by representatives of Atlas Public Health, an ELR service provider to the agency. Representatives from Atlas removed all patient identifiers from the HL7 messages, replacing existing data with the phrase "<PRESENT>" if the data did originally exist to enable data analysis without compromising patient privacy. The scrubbed messages were delivered back to the Wisconsin Department of Health Services for review. Upon approval, a representative of the Wisconsin agency uploaded the de-identified HL7 messages to a secure FTP server located at the Regenstrief Institute. The messages were then moved to the same secure server as the INPC data for analysis.

Data Quality

Much of the literature has focused on the validity of surveillance systems to produce robust signals of an emerging public health event (Bravata et al., 2004; J. W. Buehler et al., 2004; Jones & Marshall, 2004; Lombardo & Buckeridge, 2007). A critical finding from many of these studies is that the validity of surveillance systems is dependent on the quality of the data analyzed by the system (J. W. Buehler et al., 2004; Jones & Marshall, 2004). The principal role of an HIE in public health surveillance activities is to provide meaningful data to public health agencies. Therefore a prime area to examine HIE's value to public health surveillance is data quality. Previously, surveillance data quality has been defined in two dimensions: representativeness and completeness (J. W. Buehler et al., 2004).

Representativeness

First, the data should be representative of the population under investigation. This can be expressed in terms of time, place, or persons. For example, representativeness

could mean the proportion of laboratory-confirmed cases that a syndromic surveillance predicts for a given disease, like influenza (Close, Lofy, Sandifer, Lowe, & Karras, 2009). Geographic representativeness, or the proportion of a community or region analyzed by a surveillance system, is another dimension used for infectious disease (J. W. Buehler et al., 2004). Given representativeness' multiple dimensions as well as vagueness in the Buehler et al. (2004) framework regarding its use as a criterion for surveillance system selection, this study did not measure representativeness of the Indiana or Wisconsin ELR data. The study assumed the data available to the Indiana and Wisconsin state health agencies from laboratory, hospital, and HIE sources are representative of the patients living in the jurisdictions of the health departments.

Completeness

Surveillance data sent to public health should also be complete. Existing studies in public health surveillance have defined completeness as the proportion of disease incidence that should be reported to public health to effectively detect and monitor emerging disease patterns (Doyle et al., 2002; Effler et al., 1999; Nguyen et al., 2007; These studies demonstrated that electronic surveillance Panackal et al., 2002). techniques can improve reporting rates, therefore increasing the completeness of public health reports. However completeness can also be defined as "having all parts or elements; lacking nothing" ("completeness," 2004), which refers to the data in the report as well as the overall number of reports (Wurtz & Cameron, 2005). Increasing the number of reports submitted to public health agencies may not ensure the data in those reports is complete. Preliminary evidence and anecdotal information indicate that the data in electronic laboratory reports submitted to public health agencies are not always complete (M'ikanatha et al., 2003; Overhage et al., 2008). Therefore this project focused on examining the proportion of incoming ELR messages which were complete, meaning they possessed the data necessary for surveillance activities at a public health agency. This expands the traditional definition of completeness to include practical knowledge regarding the quality of the data fed into public health information systems and organizational workflows.

The HL7 fields that comprise a "minimum data set" necessary to support public health's response to an emerging health threat was identified. An initial set of important data elements was drawn from Indiana and Wisconsin state mandates, as well as existing studies that have reported on the fields used by public health agencies to perform outbreak management functions. This set was then provided to public health professionals and researchers for review. Comments and feedback were used to refine the minimum data set. The final set (described in the results section) consisted of items such as patient demographics, patient contact information, physician contact information, and details regarding the lab test and test results.

The refined minimum data set was then used to analyze and compare raw and processed HL7 message samples from Indiana and Wisconsin. The proportions of present and absent data in each field for each sample were summarized. HIE post-processed samples are likely to be more complete than the raw samples of submitted data directly from hospitals and laboratories. HIEs often possess master patient indices (eMPIs) and provider databases that can be used during the pre-processing phase to clean up message syntax, map local codes to standard vocabularies, and fill in missing values (e.g., patient address). Although some studies have described this benefit (Overhage et al., 2008), this aspect has not been empirically validated. This project will empirically validate such assertions to provide insight into which fields are often missing and qualitatively describe the impact on public health workflow associated with follow-up to acquire missing data elements.

Usefulness

In addition to completeness, Logical Observation Identifiers Names and Codes (LOINC) as well as Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT) codes were examined in select fields to assess the usefulness of the data in the messages. Usefulness here refers to the ability of the data to support public health surveillance processes via semantic interoperability. Semantic interoperability allows both the sending and receiving system to equivocally interpret the data in the messages exchanged. Lab tests vary based on laboratory equipment, methods, scales, and other

attributes of the testing process. Therefore it is important when receiving lab test information to distinguish between an Immunoassay for Chlamydia where the source was serum (LOINC code 5082-3) versus cerebral spinal fluid (LOINC code 45011-4). LOINC codes allow for universal identification of the specific lab test performed. SNOMED CT codes allow for universal identification of diseases and organisms tested for in a culture or lab test. Using standardized vocabularies in HL7 messages improves interoperability and enhances public health systems and processes that interpret the data received from hospital and lab information systems.

By examining the messages for the presence of standardized codes, the study more completely explored the ability of HIEs to support public health practice. HIE post-processed messages are hypothesized to contain greater use of standardized codes, because HIEs often actively support interoperability and the use of standards for clinical data exchange among HIE participants.

Research Questions

- Q1. What are the key fields that define a complete, minimum data set for notifiable disease surveillance?
 - Q2. How complete are electronic data submitted from laboratories and hospitals?
 - Q3. How complete are processed electronic data submitted from HIEs?
 - Q4. How well do hospital, laboratories, and HIEs support standardized vocabularies?

Survey of Public Health Surveillance Stakeholders

In addition to an empirical analysis of the completeness and usefulness of ELR data delivered to public health from an HIE, the study sought to understand the perceptions of completeness, timeliness, and usefulness of HIE-enhanced data according to the individuals and organizations involved in public health surveillance activities. The research strategy utilized to explore perceptions was a survey. The aim of the survey was to capture data on current behaviors and attitudes towards HIEs and other existing surveillance systems as well as the perceptions of completeness, timeliness, and quality of surveillance data from HIEs and the other pre-existing data sources.

Participants

The survey targeted three key stakeholder groups that participate in the collection, analysis, and response to public health threats. Public health professionals in local, state, and national public health agencies comprise the first target group surveyed. These individuals provided their perceptions of HIEs as useful systems for surveillance as well as the completeness and timeliness of various surveillance data sources including HIEs. Hospital-based infection control practitioners were also surveyed about how they perceive the impact of HIE-enhanced data on surveillance in their communities. This is the group that typically provides the most data to public health regarding emergent threats. Finally, HIEs were surveyed. This group was asked about the benefits they believe HIEs can bring to public health surveillance and the extent to which an HIE is providing services to public health agencies in the communities examined.

The survey was conducted online, because the sample population was drawn from geographically diverse states and the target respondents were likely to have access to the Internet at work and at home. Table 2 summarizes the target enrollment of survey respondents by stakeholder group in each state.

The included states were purposefully chosen. Three of the states (Indiana, Washington, and Idaho) were presumed to contain stakeholder groups with direct knowledge of HIEs or be actively working to enhance public health practice through partnerships with HIEs, because entities working in these states recently received CDC funding for enhancing public health practice using HIE. The other states were presumed to possess stakeholder groups with informal relationships with HIEs but not yet have developed enhanced surveillance activities using an HIE. Prior to including a state in the study, the researcher examined background information on the HIEs operating in the state and discussed HIE support for public health surveillance activities with a representative from the HIEs.

Study Site	Public Health Professionals	Infection Control Practitioners	HIEs
Florida	5 Local 5 State	5	2-3
Indiana	5 Local 5 State	5	1
Nebraska	5 Local 5 State	5	1
New Mexico	5 Local 5 State	5	1
Inland Northwest Region – Washington and Idaho	5 Local 5 State	5	1
CDC	5		

Table 2 - Target Enrollment of Survey Respondents

Survey Development

Likert-type survey instruments were initially developed using model questions drawn from a number of recent surveys used in public health and informatics studies (Braun et al., 2006; James W. Buehler et al., 2008; Hessler et al., 2009; NACCHO, 2009). Additional questions were developed to capture data on current public health surveillance activities, the relationships between the respondents and nearby HIEs, and attitudes towards surveillance data completeness, timeliness, and usefulness. Using several survey texts (Schuman & Presser, 1996; Tourangeau, Rips, & Rasinski, 2000), the instrument was refined prior to pilot testing. Skip logic was used to minimize burden on the respondents.

The initial surveys were pilot tested by individuals drawn from each professional group. Individuals working in Indiana were primarily selected as pilot testers due to convenience. Individuals in Nebraska and Washington also participated in the pilot testing process. Pilot testers were asked to complete the draft surveys and identify questions or terms that were ambiguous or inappropriate. Pilot testers submitted comments within the pilot survey instruments as well as email and phone conversations with the researcher. The feedback was used to modify the surveys prior to distribution

to the wider sample populations. Final survey instruments are appended as Appendix A, Appendix B, and Appendix C.

Research Questions

- Q5. What are the relationships between public health agencies and HIEs in the target areas?
- Q6. Do those individuals engaged in HIE-supported surveillance activities perceive HIE-delivered data and information to be complete, timely, of high quality, and useful?
- Q7. Do public health professionals perceive benefits in working with HIEs to improve surveillance activities?
 - Q8. What are the current gaps in surveillance processes that HIE could support?
 - Q9. What are the barriers to greater use of HIEs to support surveillance activities?

Analysis Plan

Analysis was performed in three sequential steps. First, "completeness profiles" for the ELR data extracted from real-world information systems were developed and compared. Next, the data provided by survey respondents were summarized. Finally, the methods and data from both strategies were triangulated to identify convergence and corroboration of results that address the research questions.

Analysis of Real-World Data from HL7 Messages

Samples of ELR data were obtained from two states. Two distinct samples of ELR data were obtained from Indiana and Wisconsin. One sample from each state contained data in the form of "raw" HL7 messages (ELR messages obtained directly from hospital and laboratory information systems). The other sample from each state contained data in the form of post-processed HL7 messages (ELR messages determined to be reportable results and transmitted to the state health agency).

The main unit of analysis for each sample is a "completeness profile" that describes how complete a sample is in terms of the proportion of data in the sample that can be used by public health for notifiable disease case follow-up activities. Each profile contains standardized fields derived from state law mandates, a review of the literature, and input from experts. To populate the profile, the author extracted the data from

each HL7 message within the sample into a relational database. Each column in the database table represented a given field within the HL7 message. Each row represented a unique HL7 message. The proportion of missing (or null) fields was then calculated using structured query language (SQL) statements. These values were used to populate the profiles.

In addition to the completeness profiles, the author qualitatively examined data values from select HL7 message fields. This was performed to 1) validate the results of the completeness analysis, verifying that non-null fields were actually not null; and 2) determine whether the data sender populated the field with useful information to public health surveillance processes. Useful information is defined as information that is either a) human meaningful, information that can be readily used by the public health professional receiving it; or b) semantically interoperable, data and information that can be readily used by the receiving information system at a public health agency to understand a disease or laboratory concept. SQL statements were used to group data from the various HL7 message fields for analysis.

Analysis of Survey Data

The survey data were principally analyzed using descriptive statistics. The response for many items on the survey was less than 20, which prevented the use of t-tests, regression analysis, and other rigorous statistical analyses. This was especially true for the survey of HIEs as there are few HIEs in existence in the selected states.

Some of the data collected using the surveys were qualitative in nature. For this data, a codebook was developed using themes from the study including timeliness, completeness, interoperability, satisfaction and usefulness. The codebook was used to categorize respondent's open-ended responses into similar themes that could be easily summarized and presented to the reader. The codebook is appended as Appendix D.

Triangulation of Methods and Data

Analysis of the data was completed using applied techniques from a seven-stage mixed methods process (A. J. Onwuegbuzie & Teddlie, 2003). The researcher utilized the following techniques outlined in the process: data display, data correlation, data

comparison, and data integration. The completeness profiles and survey data were charted and graphed (data display). Linkages between the various data sets were analyzed by the researcher (data correlation). Data were then compared within sets and across linkages (data comparison). Finally, the data from the various sets were integrated into a coherent group of data and information points that describe the value, real and perceived, that HIE-enhanced data and the HIE as an entity bring to public health surveillance processes.

Results

Real-World, HIE-Enhanced Public Health Surveillance Data

Assessing the value that HIEs bring to public health surveillance processes began with an examination of the completeness and usefulness of data reported to public health agencies from hospitals, laboratories, and HIEs. These dimensions of surveillance systems and data are sub-components of the framework from J.W. Buehler et al. (2004).

Completeness

To assess the impact of HIE-provided data on completeness, the researcher examined and compared electronic laboratory data received by the INPC and WDHS. The HL7 messages containing the ELR data were parsed into their respective fields for analysis. The fields selected for analysis were derived from the list of key data elements (described below) necessary to adequately perform notifiable disease surveillance. First, the key fields that together profile a data source's completeness are explained. Then the results of the empirical examination of HL7 messages from each source are described. Finally, the completeness of data from the sources is compared.

Key Fields that Define Completeness

Completeness might be considered to be in the "eye of the beholder." Yet there are methods for defining a neutral, evidence-based conception of completeness (referred to as a "completeness profile") with respect to the data provided to public health for the purpose of notifiable disease surveillance. The researcher began developing a template for the completeness profile by examining existing state laws and administrative codes that mandate which data elements are to be reported to public health agencies for notifiable conditions. The required data elements according to Indiana Administrative Code (IAC) under 410 IAC 1-2.3-48 and Wisconsin Administrative Code under HFS 145.04 for reports of notifiable disease from laboratories are summarized in Table 3. Indiana Administrative Code distinguishes between data elements that must be reported by laboratories and physicians to the state health department. Wisconsin Administrative Code, however, defines a single set of data elements that both labs and physicians must report to the WDHS.

Required Data Element	Indiana Administrative Code	Wisconsin Administrative Code
Test Name	Х	
Test Date	X	
Test Results	X	
Normal Range	X	
Laboratory Interpretation of Test Results (Findings)	Х	X
Diagnosis		Х
Date of Onset		Х
Patient Name	X	Х
Patient Address	X	X
Patient County of Residence		Х
Patient Telephone Number		Х
Patient Date of Birth or Age	Х	Х
Patient Sex		Х
Patient Race		Х
Patient Ethnicity		Х
Name of Attending Physician or Hospital or Clinic or Submitter	Х	X
Address of Attending Physician or Hospital or Clinic or Submitter	X	X
Telephone Number of Attending Physician or Hospital or Clinic or Submitter	Х	
Laboratory Accession Number	Х	
Lab Name	Х	
Lab Address	Х	
Lab Telephone Number	Х	
Lab CLIA Number	Х	

Table 3 – Data Elements Required by State Administrative Code for Notifiable

Disease Reporting

In addition to examining what is minimally required by law, the researcher examined the literature for evidence of data elements which, when provided to public health, aid

public health professionals in notifiable disease case reporting workflow. The author consulted a number of peer-reviewed ELR studies (Effler et al., 1999; Overhage et al., 2008; Panackal et al., 2002; Vogt, Spittle, Cronquist, & Patnaik, 2006) and white papers published by public health professional organizations such as the International Society for Disease Surveillance (ISDS) and the Council on State and Territorial Epidemiologists (CSTE). A summary of the key data elements reported in the literature is presented in Table 4.

Data Element	Description and Sources
Abnormal Flag	Identifies when a test result value is outside the normal range. Important for ELR and EHR systems to more intelligently flag suspicious cases. (Overhage et al., 2008)
Ethnicity	Specifies the patient's ethnicity. Important to public for tracking health care disparities. (Vogt et al., 2006)
Patient Home Phone Number	Specifies the patient's home phone number. Important for case follow-up when patient contact is necessary. (Overhage et al., 2008; Vogt et al., 2006)
Patient Identifier	Unique identifier for the patient. Supports the ability to quickly identify a patient during case report follow-up. (CSTE, 2009)
Race	Specifies the patient's race. Important to public for tracking health care disparities. (Vogt et al., 2006)
Sex (Gender)	Specifies the patient's sex. Important to public for tracking health care disparities. (Overhage et al., 2008; Vogt et al., 2006)
Specimen Source	Identifies the source of the test specimen (e.g., blood, urine). Important for mapping the result to a standardized LOINC test. (Overhage et al., 2008)
Status of Test Result	Describes whether the test is incomplete, preliminary, final, etc. Important for distinguishing final from preliminary results. (Panackal et al., 2002)

Table 4 – Key Data Elements Identified in the Literature

In addition to reviewing law and the literature, the researcher consulted a number of public health surveillance experts working at and in close proximity to Indiana University's School of Medicine. The key data elements previously described were provided to the experts for review. The experts provided feedback on the list, identifying one additional field of interest.

"Units of measure" was the data element recommended by public health informatics researchers at IU's School of Medicine. Units are associated with the

specific lab test performed to measure the amount of a substance found in the specimen or confirm the presence of absence of a disease or microorganism. Units are helpful in mapping the lab test to a standardized LOINC code, given that one of the six 'LOINC parts' is 'kind of property' or quantity and various lab tests can be distinguished based on the kinds of quantities examined in the specimen (McDonald, Huff, Mercer, Hernandez, & Vreeman, 2010). For example, the concentration of sodium in a urine sample can be measured in terms of its mass concentration (ug/mL) or molar concentration (mmol/L).

The experts further recommended eliminating some of the legally required fields from the analysis, including laboratory name, lab accession number, clinical lab identification number, lab address, and lab phone number. These fields were added to state administrative code at the request of epidemiologists at the ISDH, because under certain circumstances it is difficult to contact physicians for case report follow-up. The epidemiologists asked that labs provide this information so the lab could be contacted in cases where physicians cannot be reached. Because these data are used only in rare circumstances, these fields were excluded from this study.

The researcher then examined the HL7 technical specification to identify fields that correspond to the aggregate list of key data elements. The results of this review are summarized in Table 5. All of the key data elements were found to be present in the HL7 message specification.

Key Data Element	Corresponding HL7 Field(s)
Patient's Identifier	Patient Identifier (PID-3)
Patient's Name	Patient Name (PID-5)
Patient's Date of Birth	Date of Birth (PID-7)
Sex (Gender)	Administrative Sex (PID-8)
Race	Race (PID-10)
Patient's Address	Patient Address (PID-11)
Patient's Home Phone Number	Phone Number (PID-13)
Ethnicity	Ethnic Group (PID-22)
Specimen Source	Specimen Source (OBR-15)
Name of Attending Physician or	Ordering Provider (OBR-16)
Hospital or Clinic or Submitter	Ordering Facility Name (ORC-21)
	Staff Name (STF-3)

Telephone Number of Attending	Order Callback Phone Number (OBR-17)
Physician or Hospital or Clinic or	Ordering Facility Phone Number (ORC-23)
Submitter	Staff Phone (STF-10)
Address of Attending Physician or	Staff Office/Home Address (STF-11)
Hospital or Clinic or Submitter	Ordering Provider Address (ORC-24)
Test Name	Observation Identifier (OBX-3)
Test Results or Laboratory	Observation Value (OBX-5)
Interpretation of Test Results	
Units of Measure	Units (OBX-6)
Normal Range	Reference Range (OBX-7)
Abnormal Flag	Abnormal Flags (OBX-8)
Status of Test Result	Observation Result Status (OBX-11)

Table 5 – Key Data Elements and their HL7 Field Equivalents

Table 5 became the template to "profile" completeness with respect to a given data set from a particular data source. The researcher used the completeness profile template to empirically examine ELR messages from the INPC and WDHS.

Empirical Analysis of Real-World ELR Messages

Four samples of real-world surveillance data were collected from two sources. Each source provided two samples of data in the form of HL7 messages. The various samples are described and their completeness profiles presented in this section.

Sample 1 – ELR Data from Indiana Hospitals and Laboratories

The first sample contained 7,592,039 HL7 messages extracted from the INPC's "raw" queue for incoming messages. This set represents the complete set of electronic messages received from an INPC participant (e.g., hospital, lab) and flagged for consideration by the Regenstrief Notifiable Condition Detector (NCD) between November 14, 2010 and December 15, 2010.

The messages include several HL7 message types, summarized in Table 6. ORU messages account for the largest proportion of the sample (92%). ORM messages comprise the next largest proportion of the sample (3.7%). BAR messages account for approximately two percent of the sample. MDM messages account for around one percent of the sample. Three varieties of ADT messages complete the sample.

HL7 Message Type	Description	Number
ORU^R01	Unsolicited observation result – clinical observation data, ranging from laboratory results to clinician notes	6,981,067
ORM^O01	Order messages – lab and other orders entered by clinicians	281,094
BAR^P01	Billing account record – transmitted when a patient is registered in the heath care facility	159,731
MDM^T01	Medical document management – updates on the availability and changes to medical documents	83,616
ADT^A04	Admission, discharge, and transfer – indicates when a patient arrives for treatment or is transferred to another department or care setting	64,276
ADT^A03	Same as ADT^A04	17,940
ADT^A01	Same as ADT^A04	4,315

Table 6 – HL7 Message Types Found in Raw Indiana Messages

There are 7,471,001 observation request (OBR) segments and 22,244,305 observation result (OBX) segments in the sample. Each OBR segment can contain multiple OBX segments, which is why this number is larger than the total message count and the OBR count. There are roughly 2.98 OBX segments per OBR segment. OBR segments provide details on laboratory orders placed by a clinician or provider organization. OBX segments provide the detailed information about the lab test performed and the resulting value. In the public health use case, the OBR segment describes the metadata concerning the lab test (e.g., who ordered it, when was it ordered) while the OBX segment contains the clinical evidence that a patient has a given notifiable disease (e.g., the test results).

The completeness profile for the INPC "raw" data is presented in Table 7. The "Values Present" column contains the count of distinct HL7 fields within a given HL7 segment in which a value other than null or empty string ("") was provided by the source (e.g., hospital, lab) information system. Each field's "percent complete" was calculated by dividing the count of non-null values by the total number of possible field

values within a given HL7 segment. Since there were 7,592,039 messages in the set, there were 7,592,039 possible PID-3 values. There were 7,471,001 possible values for fields within the OBR segment, and there were 22,244,305 possible values for fields within the OBX segments.

Key Data Element	Corresponding HL7 Field	Values Present	Percent Complete
Patient's Identifier	Patient Identifier (PID-3)	7,589,435	99.9%
Patient's Name	Patient Name (PID-5)	7,545,252	99.4%
Patient's Date of Birth	Date of Birth (PID-7)	7,421,611	97.8%
Sex (Gender)	Administrative Sex (PID-8)	7,272,956	95.8%
Race	Race (PID-10)	2,912,486	38.4%
Patient's Address	Patient Address (PID-11)	3,150,408	41.5%
Patient's Home Phone Number	Phone Number (PID-13)	2,922,198	38.5%
Ethnicity	Ethnic Group (PID-22)	262,883	3.5%
Specimen Source	Specimen Source (OBR-15)	1,021,533	13.7%
Name of Attending Physician or Hospital or Clinic or Submitter	Ordering Provider (OBR-16)	4,284,984	57.4%
Telephone Number of Attending Physician or Hospital or Clinic or Submitter	Callback Number (OBR-17)	11,045	0.15%
Test Name	Observation Identifier (OBX-3)	22,088,037	99.3%
Test Results or Laboratory Interpretation of Test Results	Observation Value (OBX-5)	21,420,292	96.3%
Units of Measure	Units (OBX-6)	12,673,206	57.0%
Normal Range	Reference Range (OBX-7)	12,403,198	55.8%
Abnormal Flag	Abnormal Flags (OBX-8)	7,327,231	33.0%
Status of Test Result	Observation Result Status (OBX-11)	20,647,972	92.8%

Table 7 – Completeness Profile for INPC "Raw" Message Sample

Sample 2 – ELR Data from the Indiana Network for Patient Care

The next sample contains 16,365 messages extracted from the Regenstrief NCD post-processed queue. This set represents the complete set of electronic messages examined by the Regenstrief NCD, determined to be reportable, and subsequently reported to the ISDH, between November 14, 2010 and December 15, 2010. These

messages are also post-processed messages, meaning that they have undergone cleansing and normalization processes by Regenstrief, where local lab codes are mapped to LOINC and provider information has been enhanced using Regenstrief's Master Provider Index.

There are two types of HL7 messages in the set, summarized in Table 8. The set principally contains ORU messages.

HL7 Message Type	Number
ORU^R01	16,189
ADT^A03	176

Table 8 – HL7 Message Types Found in Reportable Indiana Messages

There are 35,266 OBR segments and 131,665 OBX segments in the sample of INPC reportable messages, which equates to 3.73 OBX segments per OBR.

The completeness profile for the INPC mapped sample is presented in Table 9. The "Values Present" column contains the count of distinct HL7 fields within a given HL7 segment in which a value other than null or empty string ("") was provided by the sending source information system. Each field's "percent complete" was calculated by dividing the count of non-null values by the total number of possible field values within a given HL7 segment.

Key Data Element	Corresponding HL7 Field	Values	Percent
		Present	Complete
Patient's Identifier	Patient Identifier (PID-3)	16,365	100%
Patient's Name	Patient Name (PID-5)	16,365	100%
Patient's Date of Birth	Date of Birth (PID-7)	16,338	99.8%
Sex (Gender)	Administrative Sex (PID-8)	16,353	99.9%
Race	Race (PID-10)	9,873	60.3%
Patient's Address	Patient Address (PID-11)	10,357	63.3%
Patient's Home Phone	Phone Number (PID-13)	11,918	72.8%
Number			
Ethnicity	Ethnic Group (PID-22)	3,001	18.3%
Specimen Source	Specimen Source (OBR-15)	10,135	28.7%
Name of Attending	Staff Name (STF-3)	15,748	66.5%
Physician or Hospital or			
Clinic or Submitter			
Telephone Number of	Staff Phone (STF-10)	11,535	73.3%
Attending Physician or			

Hospital or Clinic or Submitter			
Address of Attending Physician or Hospital or Clinic or Submitter	Staff Office/Home Address (STF-11)	13,327	84.6%
Test Name	Observation Identifier (OBX-3)	131,665	100%
Test Results or Laboratory Interpretation of Test Results	Observation Value (OBX-5)	130,264	98.9%
Units of Measure	Units (OBX-6)	22,998	17.5%
Normal Range	Reference Range (OBX-7)	24,120	18.3%
Abnormal Flag	Abnormal Flags (OBX-8)	37,443	28.4%
Status of Test Result	Observation Result Status (OBX-11)	130,953	99.5%

Table 9 – Completeness Profile for INPC "Reportable" Message Sample

Prior to consideration by the NCD, Regenstrief identifies all of the providers mentioned in the message and resolves their identity using its Master Provider Index. Regenstrief then appends a Staff (STF) segment onto the message, and the STF segment is populated with data from the Master Provider Index for each provider identified in the message. Therefore the STF segments were used to calculate the completeness of the NCD messages with respect to provider name, phone, and address.

Regenstrief identified providers in 8,420 messages (51.5%) from the NCD sample. There are 23,694 providers identified in the messages; roughly 3 providers per message (e.g., ordering physician, attending physician, lab technician). Of the identified providers, 15,748 providers (66.5%) are mapped to a standardized identifier (e.g., National Provider Identifier or NPI) in the Regenstrief Master Provider Index. For those providers with a valid identifier, 11,535 providers (73.3%) have a phone number and 13,327 providers (84.6%) have an address.

Sample 3 – ELR Data from Wisconsin Hospitals and Laboratories

The final sample contains 222,335 HL7 message segments extracted from the Wisconsin Department of Health Services (WDHS) queue of ELR messages. These messages represent a random sample of ELR messages received by WDHS between May 3, 2007 and November 18, 2010. These messages all represent a reportable disease under Wisconsin state law.

The sample contains two subsets of messages. First, the sample contains a set of messages labeled as "original" messages. These messages represent the "raw," incoming messages from laboratory information systems within hospitals, independent labs, and the state health lab. The second set of messages is labeled "phil" and represents post-processed messages which have been mapped to LOINC and SNOMED by the Atlas PHIN Suite's Public Health Information Link (PHIL) software component.

The sample includes only ORU^R01 messages. There are 231,077 OBR segments and 319,744 OBX segments in the sample. This equates to 1.38 OBX segments per OBR.

Table 10 provides the completeness profile for the key fields from this sample. Since the only substantive difference between the "original" and "phil" messages are mapped LOINC and SNOMED codes, the sample was profiled and analyzed as a whole and not divided into two distinct subsets.

Key Data Element	Corresponding HL7 Field	Values	Percent
		Present	Complete
Patient's Identifier	Patient Identifier (PID-3)	222,332	99.9%
Patient's Name	Patient Name (PID-5)	221,868	99.8%
Patient's Date of Birth	Date of Birth (PID-7)	219,040	98.5%
Sex (Gender)	Administrative Sex (PID-8)	218,458	98.3%
Race	Race (PID-10)	136,594	61.4%
Patient's Address	Patient Address (PID-11)	199,185	89.6%
Patient's Home Phone	Phone Number (PID-13)	78,764	35.4%
Number			
Ethnicity	Ethnic Group (PID-22)	32,096	14.4%
Specimen Source	Specimen Source (OBR-15)	209,368	90.6%
Name of Attending	Ordering Provider	212,464	92.0%
Physician or Hospital or	(OBR-16)		
Clinic or Submitter			
Telephone Number of	Ordering Facility Phone	220,309	99.1%
Attending Physician or	Number (ORC-23)		
Hospital or Clinic or			
Submitter			
Address of Attending	Ordering Provider Address	221,066	99.4%
Physician or Hospital or	(ORC-24)		
Clinic or Submitter			
Test Name	Observation Identifier (OBX-3)	319,744	100%
Test Results or	Observation Value (OBX-5)	319,744	100%
Laboratory Interpretation			

of Test Results			
Units of Measure	Units (OBX-6)	132,859	41.6%
Normal Range	Reference Range (OBX-7)	60,668	19.0%
Abnormal Flag	Abnormal Flags (OBX-8)	212,468	66.4%
Status of Test Result	Observation Result Status	318,044	99.5%
	(OBX-11)		

Table 10 – Completeness Profile for WDHS Notifiable Condition Messages

The Wisconsin messages use a combination of the OBR and the Common Order (ORC) segments to provide information on the facility and provider which ordered the test. Therefore the researcher examined the OBR-16, ORC-23, and ORC-24 fields to assess completeness with respect to provider name, phone, and address. There was one ORC segment per message, and the fields were nearly 100 percent complete.

Completeness Comparisons

The completeness profiles for the samples from Indiana and Wisconsin that contain reportable results are compared in Table 11. The absolute difference between the two samples is provided in the last column. In some instances, a field is more complete in the Indiana sample. In other instances, a field is more complete in the Wisconsin sample.

Key Data Element	% Complete INPC NCD	% Complete WDHS	Difference
Patient's Identifier	100%	99.9%	0.01%
Patient's Name	100%	99.8%	0.02
Patient's Date of Birth	99.8%	98.5%	1.3%
Sex (Gender)	99.9%	98.3%	1.6%
Race	60.3%	61.4%	1.1%
Patient's Address	63.3%	89.6%	26.3%
Patient's Home Phone Number	72.8%	35.4%	37.4%
Ethnicity	18.3%	14.4%	3.9%
Specimen Source	28.7%	90.6%	61.9%
Name of Attending Physician or Hospital or	66.5%	92.0%	25.5%
Clinic or Submitter			
Telephone Number of Attending Physician	73.3%	99.1%	25.8%
or Hospital or Clinic or Submitter			
Address of Attending Physician or Hospital	84.6%	99.4%	14.8%
or Clinic or Submitter			
Test Name	100%	100%	

Test Results	98.9%	100%	1.1%
Laboratory Interpretation of Test Results			
Units of Measure	17.5%	41.6%	24.1%
Normal Range	18.3%	19.0%	0.7%
Abnormal Flag	28.4%	66.4%	38.0%
Status of Test Result	99.5%	99.5%	0.01%

Table 11 – Comparing Completeness of Indiana and Wisconsin Reportable

Messages

The author further compared the completeness of the "raw sample" from Indiana with the "enhanced sample" that is the output of the Regenstrief NCD. This comparison is shown in Table 12. Again, the absolute difference between the percent complete of each field is provided in the last column.

Key Data Element	% Complete INPC Raw	% Complete INPC NCD	Difference
Patient's Identifier	99.9%	100%	0.01%
Patient's Name	99.4%	100%	0.06%
Patient's Date of Birth	97.8%	99.8%	2.0%
Sex (Gender)	95.8%	99.9%	4.1%
Race	38.4%	60.3%	21.9%
Patient's Address	41.5%	63.3%	21.8%
Patient's Home Phone Number	38.5%	72.8%	34.3%
Ethnicity	3.5%	18.3%	14.8%
Specimen Source	13.7%	28.7%	15.0%
Name of Attending Physician or Hospital or Clinic or Submitter	57.4%	66.5%	8.9%
Telephone Number of Attending Physician or Hospital or Clinic or Submitter	0.15%	73.3%	73.2%
Address of Attending Physician or Hospital or Clinic or Submitter	N/A	84.6%	N/A
Test Name	99.3%	100%	0.07%
Test Results	96.3%	98.9%	2.6%
Laboratory Interpretation of Test Results			
Units of Measure	57.0%	17.5%	39.5%
Normal Range	55.8%	18.3%	37.5%
Abnormal Flag	33.0%	28.4%	4.6%
Status of Test Result	92.8%	99.5%	6.7%

Table 12 - Comparing the Completeness of Raw versus INPC Processed Messages

Usefulness

In addition to completeness, the usefulness of the data in the HL7 messages was analyzed. The values from select HL7 fields (OBX-3 and OBX-5) were grouped and manually reviewed by the researcher. Standardized values from the LOINC and SNOMED CT vocabularies were identified, and the proportion of the values for a given field were calculated. The higher the proportion of values within a field contain either LOINC or SNOMED concepts, the more semantically interoperable the field in a given sample of messages.

The HL7 fields analyzed included the OBX-3 and OBX-5. The Observation Identifier (OBX-3) field contains coded data elements (HL7 data type CE). The field stores triplicate, repeatable values that consist of a code, which is a mnemonic representation of a concept (e.g., 123); a description of the code value, which defines the concept that the code represents (e.g., "lead test"); and coding system, which describes the organization or standards body that maintains the code list and definitions (e.g., "MyLab"). The OBX-5 (Test Results) field can contain any one of the various HL7 data types, including coded (CE), free text (TX), and number values (NM). The field stores the results of a laboratory test. For quantitative lab tests, this field stores number values. For microbiology cultures, this field often contains the findings, interpretations, and comments from the lab technician.

Sample 1 – ELR Data from Indiana Hospitals and Laboratories

An analysis of the OBX-3 fields for the "raw" data sent to the INPC from Indiana hospitals and labs revealed that 3,724 values (<1.0%) represent standardized test values using the LOINC vocabulary. The remaining values (99.9%) represent local laboratory and source system codes.

A similar analysis of the OBX-5 fields from this sample was performed to identify the percentage of fields that contain standardized test result values drawn from the SNOMED CT vocabulary. Seven OBX-5 values (<0.01%) represent standardized SNOMED CT concepts, which is a fraction of both the overall OBX-5 fields and the OBX-5 fields that are of type CE from this sample.

Sample 2 – ELR Data from the Indiana Network for Patient Care

Similar analyses were performed on the sample of ELR data that are processed by the Regenstrief NCD. There are 2,703 messages (16.5%) in this sample which contain a LOINC code in one of the "original" OBX-3 field sections. These standardized values were reported by the data sender to the INPC. All of these messages report lead exposure results, using one of the following LOINC codes: 10368-9 (Lead BldC-mCnc) or 5671-3 (Lead Bld-mCnc). Furthermore, the sources of these messages are large, mostly national, send out laboratories and the state's public health lab.

In addition to LOINC codes supplied by the data sender, there are 16,365 messages (100%) which contain at least one "mapped" LOINC code in the OBX-3 field. These LOINC codes are mapped by internal INPC processes, in which messages are "cleaned up" and semantic meaning is translated. These translations are typically created manually by experienced lab technicians at Regenstrief who link, for example, an incoming OBX segment for "755759^Strep Grp A Ag QL" to "18481-2^Streptococcus pyogenes Ag [Presence] in Throat." The mappings are stored and applied as the INPC encounters similar lab messages in the future.

In addition to mapping the reported observations to LOINC, the Regenstrief NCD adds a unique, LOINC-encoded OBX segment to all messages for which there is a reportable result that is ultimately sent to public health agencies. This new OBX segment contains an OBX-3 value of 54217-5 (Public health notifiable condition) and an OBX-5 value that explicitly states the notifiable condition found in the message (e.g., "Lead exposure," "Pneumonia," "Human immunodeficiency virus").

With respect to SNOMED CT, none of the OBX-5 fields (0.0%) in this sample contain SNOMED-encoded values. The INPC does not attempt to map OBX-5 values to SNOMED CT concepts during its routine message processing.

Sample 3 – ELR Data from Wisconsin Hospitals and Laboratories

None of the WDHS "original" OBX-3 segments (0.0%), the messages sent to the WDHS directly from hospitals and labs, contain a LOINC-encoded result. All results from this subset (100%) of the sample are reported as local codes. On the other hand, all

OBX-3 segments in the "phil" subset (100%), messages received by the WDHS and subsequently mapped by the Atlas PHIL software, contain LOINC concepts mapped to the original, local codes.

With respect to SNOMED CT, there are 8,612 OBX-5 fields in the "original" subset from WDHS that contain SNOMED-encoded values mapped to local codes. The SNOMED-encoded values represent 3.2% of all OBX-5 fields in the subset and 12.3% of OBX-5 fields of type CE in the subset. In the "phil" subset, the messages received by the WDHS and mapped by the Atlas PHIL software, there are 9,868 OBX-5 fields that contain SNOMED concepts mapped to the original, local codes. These values represent 20.0% of all OBX-5 fields in the subset and 47.6% of OBX-5 fields of type CE in the subset.

Usefulness Comparisons

The usefulness, or semantic interoperability, of each sample is summarized in Table 13 and Table 14 for comparison. All message samples improved in usefulness following a mapping process in which local concepts were translated using standardized vocabularies. The WDHS sample showed the largest improvements. However, the improvement with respect to LOINC was equal if the large, send out lead tests included in one of the INPC samples are ignored.

Sample	% Original OBX-3 Fields with LOINC	% Mapped OBX-3 Fields with LOINC	Difference
INPC "Raw" Messages	<1.0%	N/A	N/A
INPC "Processed" Messages	16.5%	100%	83.5%
WDHS Messages	0.0%	100%	100%

Table 13 - Proportion of ELR Data Samples with LOINC Concepts

Sample	% Original OBX-5 CE Fields with SNOMED	% Mapped OBX-5 CE Fields with SNOMED	Difference
INPC "Raw" Messages	<0.01%	N/A	N/A
INPC "Processed" Messages	0.0%	0.0%	0.0%
WDHS Messages	12.3%	47.6%	35.3%

Table 14 - Proportion of ELR Data Samples with SNOMED Concepts

<u>Perceptions of Public Health Surveillance Processes and HIE</u>

In addition to examining the completeness and usefulness of real-world surveillance data, the researcher also surveyed perceptions of surveillance data completeness, timeliness, and usefulness. Surveys were provided to three distinct stakeholder groups in the six target states. The results of the surveys are now described.

Public Health Professionals

The author invited 143 public health professionals via email to participate in the survey (Appendix A). The National Association of City and County Health Officials (NACCHO) provided the author with a list of local health departments from its membership database. This database contained 250 local health departments (LHDs) for the states targeted in the study (Florida, Indiana, Nebraska, New Mexico, and Washington). Using the public Internet, the author obtained email addresses for public health officials and communicable disease coordinators at 138 of the 252 LHDs. The author further obtained email addresses of individuals working for the six state health agencies (SHAs) as well as the former CDC National Center for Public Health Informatics.

Each individual received an invitation to take the survey along with a link to the online survey. Most of the LHDs and SHAs posted a single, generic email address for the LHD or SHA on their website. Therefore the email invitations asked the recipient to forward the survey request to the most appropriate resource at the agency.

Seventy-three public health professionals (51.0% of the target sample) responded to the survey. Ultimately 16 surveys were discarded. Surveys were considered complete if the respondent answered at least one of the sections on either notifiable disease or syndromic surveillance even if the respondent didn't answer all of the questions in both sections. Fourteen of the surveys were incomplete, meaning that the respondents provided limited demographic data regarding the public health departments but did not answer any questions about notifiable disease or syndromic surveillance practices. Furthermore, one survey was completed by an employee whose role at the agency is limited to environmental protection. Finally, three surveys were combined to represent a "single view" for a given LHD. Combining responses was necessary because one health

department contacted the researcher to inform him that the public health nurse completed only the section on notifiable reporting while the epidemiologist completed only the section on syndromic surveillance. The researcher combined the survey responses into a single response across all dimensions of the survey. Once the responses were cleaned, 56 complete surveys from public health professionals (39.2% of the initially targeted sample) were included for analysis.

The final pool of respondents is diverse in terms of public health jurisdiction, geography, and population size. Table 15 shows the distribution of respondents based on public health jurisdiction. All but six respondents represented local health departments (LHDs). Within the LHD respondent pool, most represented county-level LHDs while a few represented city and tribal region LHDs. Figure 2 displays the number of respondents based on the population of the LHD jurisdictions. State jurisdictions were excluded from this figure because their populations were all over one million, which would have skewed the figure. LHD populations appear normal in their distribution from small (less than 25,000) to large (over one million). Finally, respondents are distributed across several U.S. states (see Figure 3). New Mexico may appear to be under-represented. However, that state only has five logical public health jurisdictions, two of which responded to the survey invitation. Florida may be slightly under-represented as it does have a number of county-level health departments that did not respond to the survey invitation. The response from Oregon is an anomaly as the researcher did not target this state, but a LHD on the other side of the border from Washington learned about the survey and completed it. Overall, therefore, no major biases based on jurisdiction, population, or geography appear to be present in the sample.

Jurisdiction	Number	Percentage
City	2	3.6%
County	36	65.5%
Multi-County	10	18.2%
State	6	10.9%
Tribal	1	1.8%

Table 15 – Distribution of PH Respondents by Jurisdiction (N=55)

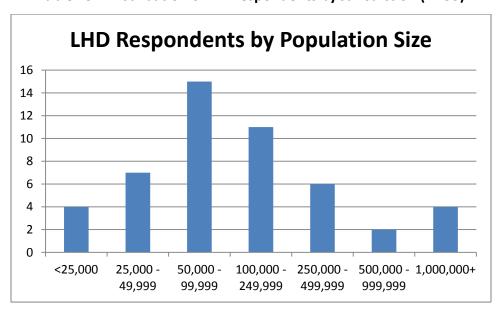


Figure 2 – Distribution of LHD Respondents by Population (N=49)

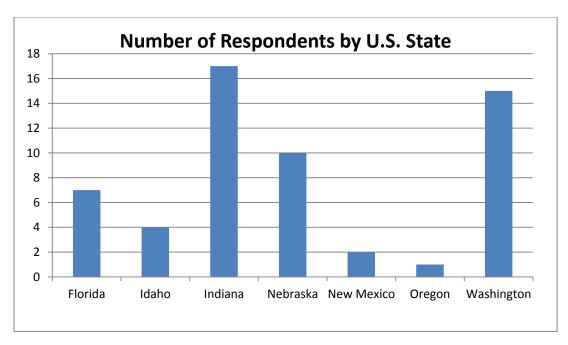


Figure 3 – Distribution of Respondents by U.S. State (N=56)

Respondents to the public health survey tended to be part of their agencies' executive management teams (see Figure 4). This role included elected public health officials as well as directors of public health nursing and epidemiology programs (48.2% of all respondents). Respondents who did not describe themselves as managers tended to label themselves as either epidemiologists (23.2%) or public health nurses (14.3%). The remaining respondents indicated they worked in the health agency's IT department (8.9%) or selected "Other" and entered a custom value such as "Assessment Coordinator."

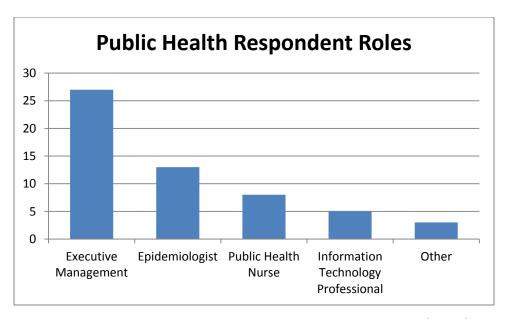


Figure 4 – PH Respondents Roles within their PH Agencies (N=56)

Few public health agencies indicated they were active participants of an organized HIE entity. When asked to describe their agency's relationship with nearby HIEs, most respondents indicated either a) no HIE existed within their service area (17.9%); b) there was no relationship between the agency and known HIEs (19.6%); or c) the agency had only an informal relationship with the HIE (33.9%). Only 14 (25.0%) of respondents indicated their agency had a formal relationship, typically created through a memorandum of understanding or data usage agreement, with at least one nearby HIE. This is summarized in Figure 5.

Respondents were asked in a separate question whether or not their public health agency actively exchanged data with a nearby HIE entity. 18 respondents (32.7%) responded in the affirmative, while 28 respondents (50.9%) responded in the negative. Nine respondents (16.4%) answered "I Don't Know" to the question.

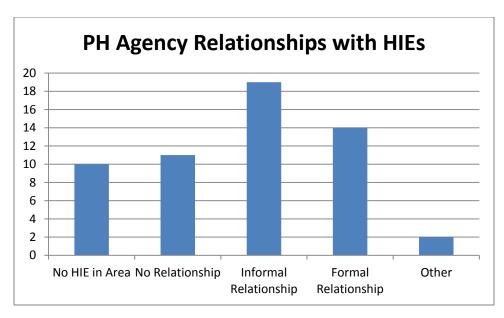


Figure 5 – PH Agency Relationships with Nearby HIEs (N=56)

Since the researcher hypothesized that few public health agencies would be actively involved in data exchange with an HIE entity, the survey contained questions to understand how agencies currently exchange data for notifiable conditions and syndromic surveillance. The questions asked the respondents to indicate which methods were principally used to collect data from healthcare providers for case reports and surveillance statistics. The survey further asked agencies to indicate the methods they employ to share information collected with their partners (e.g., other LHDs, the CDC).

Receiving Notifiable Condition Data

The survey asked respondents to provide details about how their public health agency currently receives notifiable disease surveillance data. Fifty-two (92.9%) respondents completed this section of the survey. The various methods that respondents indicated are used by their agencies to receive data on notifiable conditions are displayed in Figure 6. Respondents could select more than one method. The first three methods are highly manual processes that require public health agency staff to transfer the information received from health care providers into the computer applications used at the agency to perform surveillance activities. The latter three methods use electronic methods to capture data and transfer them into agency

computer systems. The most common reported method to capture notifiable condition data is the fax machine, where providers fax lab results to the public health agency. Forty one (78.9%) of the 52 responding agencies reported that their agency receives at least a portion of its notifiable condition data in the manner. Thirty three respondents (62.5%) indicated their agencies receive a portion of the data via postal mail. Ten respondents (19.2%) reported their agencies use email to receive some of the data. Approximately half of the respondents reported receiving some of their data electronically. Some agencies (46.2%) use a Web-based reporting system, where providers manually input data into a Internet application hosted by the agency. Other agencies use ELR (55.8%), where laboratory data is transmitted directly to the agency from a laboratory or hospital information system. Ten agencies (19.2%) reported using an HIE to receive a portion of their notifiable disease data.

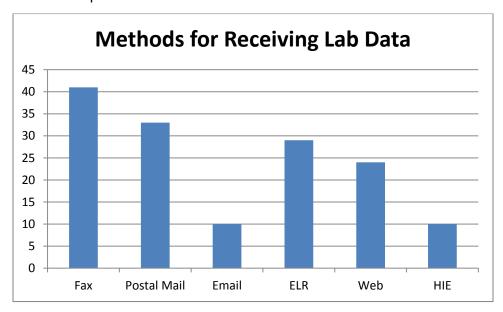


Figure 6 – Methods for Public Health Agencies to Receive Laboratory-Based Data (N=52)

In addition to examining which methods were available for use, the survey asked respondents to indicate the proportion of lab data received via each method. This helped the researcher to understand the dominant methods used by each agency to collect notifiable disease data, since only six respondents (11.5%) indicated their agency only used a single method for data collection. For each of 48 respondents who provided

proportion information, the researcher identified the method that was used to collect the highest proportion of data for the agency. That became the agency's "principal method" for receiving lab data. For example, one respondent indicated her agency receives 80 percent of its data via ELR, but the agency receives the remaining 20 percent of its data via fax. Here the principal method would be ELR. The principal methods are summarized in Figure 7. Figure 8 displays the principal methods for laboratory data receipt based on the agencies' population size. One third of agencies (33.3%) indicated that ELR was the dominant method by which they received notifiable data. This was primarily state agencies and LHDs with larger populations (greater than 100,000 people). Fax (29.2%) and Web-based (20.8%) methods were the next most common principal methods used by agencies. These methods were most popular with LHDs whose populations were between 50,000 and 250,000. HIE was the principal method used by only five agencies (10.4%). Interestingly, these agencies were LHDs whose populations were between 25,000 and 99,999.

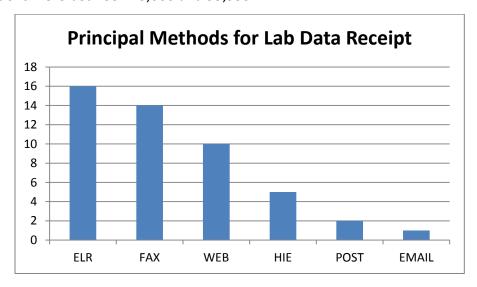


Figure 7 – Principal Methods for Receiving Laboratory Data (N=48)

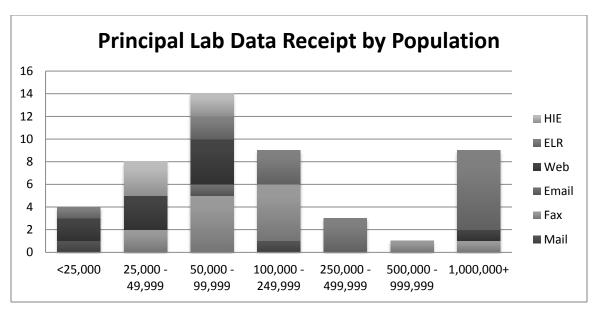


Figure 8 – Principal Methods for Receiving Lab Data By Population Size (N=45)

Receiving Syndromic Surveillance Data

Respondents were also asked similar questions regarding how their agencies receive syndromic surveillance data. Forty-one respondents (73.2%) completed this section of the survey. Figure 9 summarizes the various methods used by public agencies to receive at least a portion of their syndromic surveillance data. Email (41.5%), Web-based entry (39.0%), and fax (34.2%) were the methods reported most often by respondents. Electronic receipt, either directly from the provider organization or via HIE, was reported by 18 (44.0%) respondents. Postal mail (14.6%) was reported much less frequently than for the receipt of notifiable disease data. Respondents could again choose more than one method, however 17 of the 41 respondents (38.6%) selected only a single method.

The principal methods used by each agency were also analyzed, and the information is summarized in Figure 10. Email (22.5%) and fax (20.0%), methods, which require public health to manually aggregate incidence across the jurisdiction, accounted for nearly half of the principal methods reported. None of the agencies reported postal mail to be a principal method by which they receive syndromic data. A sub-analysis of the syndromic data receipt methods based on agency population size was again performed, and the results are displayed in Figure 11. Receiving data directly from

provider systems or from an HIE was reported primarily by agencies serving populations greater than 250,000.

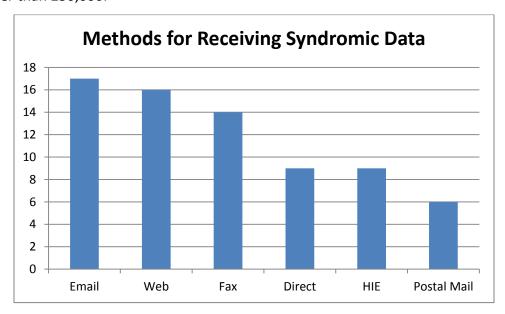


Figure 9 – Methods for Public Health Agencies to Receive Syndromic Data (N=41)

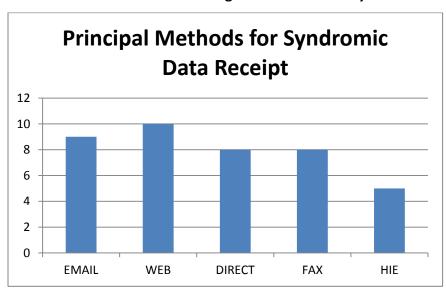


Figure 10 – Principal Methods for PH Receipt of Syndromic Surveillance Data (N=41)

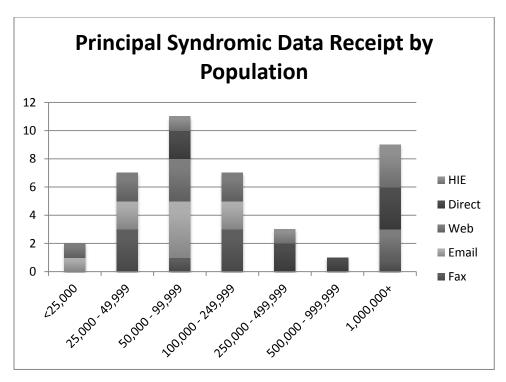


Figure 11 – Principal Syndromic Data Receipt by Population (N=41)

Public Health Communication of Surveillance Data

The survey further asked respondents about their agencies' methods for communicating surveillance data and information relevant to their jurisdiction. Public health agencies routinely share information, for example, with other agencies as well as the public. Figure 12 displays the range of methods provided by respondents who completed this section of the survey (N=52). The majority of agencies (75.0%) indicated they communicate to partners and community stakeholders using an electronic newsletter. Half of the respondents (51.9%) indicated they share information by entering data into Web-based reporting software. These respondents were primarily LHDs which likely report or access their surveillance information via Web applications hosted by their respective SHAs. In Indiana, for example, LHDs log into an online application, ESSENCE, maintained by the SHA. The SHA collects syndromic surveillance data from emergency department information systems, through an HIE, and feeds the data into ESSENCE. Just under half of respondents (46.2%) indicated their agencies print letters and put them in the postal mail to providers or other stakeholders. All but one of the respondents who selected this method were LHDs.

Usage of the Public Health Information Network (PHIN) to share surveillance information was reported by 18 of the 52 respondents (34.6%). Of the respondents who indicated their agency used PHIN to share information with other public health agencies, the majority of the respondents (77.8%) work for agencies that serve populations equal to or greater than 100,000. The Nationwide Health Information Network (NwHIN) was also a method that could be selected by respondents. Six respondents (11.6%) indicated this is a method used by their agency. Of these respondents, five (83.3%) work for an agency that is formally partnered with an HIE, and three of these respondents (50.0%) work for SHAs.

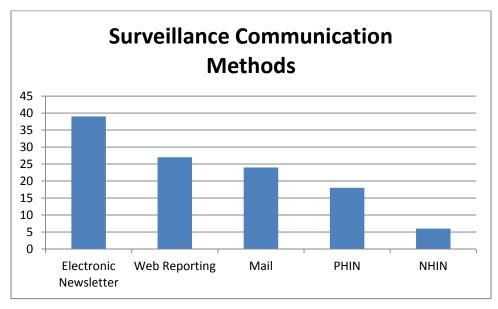


Figure 12 – Surveillance Data and Information Communication Methods (N=50)

Perceptions of HIE

All respondents were asked five very broad questions about HIE. Perceptions were measured on a five point Likert scale from 1 (Strongly Disagree) to 5 (Strongly Agree). The mean value for each question and standard deviations across all respondents is presented in Table 16. Higher values indicate positive perceptions of HIE for the two positively worded items. Lower values indicate positive perceptions of HIE for the three negatively worded items.

On average, respondents "somewhat agreed" that participation in HIEs supports the public good. Similarly, respondents generally agreed that they would recommend

participation in an HIE to colleagues in other health departments. Respondents generally disagreed that they lack an understanding of why a public health department would want to exchange with an HIE. Respondents further disagreed that they held concerns that HIEs would have a negative impact on privacy and public health practice.

Survey Item	Mean	Standard Deviation
Participation in an HIE supports the public good	4.0	1.1
Recommend participating in an HIE to colleagues in other health departments	3.8	1.2
I do not understand why public health should be involved with HIE projects*	1.8	0.9
Concern that HIE will have a negative impact on public health practice*	2.2	1.3
Concern that HIE will have a negative impact on patient privacy*	2.2	1.3

Table 16 – Perceptions of HIE by Public Health Respondents (N=39); *Indicates a negatively worded item

A sub-analysis was performed to understand perception differences between agencies that currently exchange data with HIEs versus those that are not currently exchanging data with an HIE. The researcher hypothesized that there would be generally more positive perceptions of HIEs by those agencies that currently exchange data with an HIE.

Indeed individuals at agencies that exchange data with an HIE generally held more positive perceptions of HIEs than did those individuals at agencies which do not exchange data. The mean values for each item among the two groups are summarized in Table 17. There is very little difference in the mean values for the last two items which asserts that HIE might have a negative impact on privacy and public health practice.

Survey Item	Agencies Exchanging Data with HIEs N = 15	Agencies Not Exchanging Data with HIEs N = 18
Participation in an HIE supports the public good	4.3	3.9
Recommend participating in an HIE to colleagues in other health departments	4.1	3.6
I do not understand why public health should be involved with HIE projects*	1.5	2.0
Concern that HIE will have a negative impact on public health practice*	2.3	2.2
Concern that HIE will have a negative impact on patient privacy*	2.1	2.3

Table 17 – Perceptions of HIE by Agencies which Do and Do Not Exchange Data with an HIE (N=33); *Indicates a negatively worded item

The researcher performed a second sub-analysis to detect differences among those states and regions where the CDC recently invested in regional HIEs and those areas where there hasn't been investment in HIE. The CDC funded HIE development in Indiana and the Inland Northwest region (Washington, Idaho, and Oregon). These investments were aimed at developing better situational awareness through HIE-enhanced biosurveillance methods and technologies (Dobbs, Trebatoski, & Revere, 2010; Gamache, Stevens, Merriwether, Dixon, & Grannis, 2010; S. J. Grannis, Stevens, & Merriwether, 2010).

Respondents in areas that received funds from CDC to integrate HIEs and public health agency information systems generally perceived HIE more positively than those areas surveyed without such investment. This difference was most notable for the item that asked respondents if participation in an HIE supported the public good and if the respondent would recommend participating in an HIE to public health colleagues.

Survey Item	Areas with CDC Investment N=26	Areas without CDC Investment N=13
Participation in an HIE supports the public good	4.2	3.5
Recommend participating in an HIE to colleagues in other health departments	4.1	3.3
I do not understand why public health should be involved with HIE projects*	1.7	2.0
Concern that HIE will have a negative impact on public health practice*	2.3	1.9
Concern that HIE will have a negative impact on patient privacy*	2.2	2.0

Table 18 – Perceptions of HIE by Public Health Agencies by CDC Investment Area (N=39); *Indicates negatively worded item

Respondents were asked whether or not their PH agency used "one or more computer systems/applications to view and/or analyze laboratory-reported data for notifiable conditions." Fourty-four respondents (78.57%; N=56) answered in the affirmative. Of these 44 respondents, 36 (81.8%) provided the names of their computer systems and applications. Twenty-nine (80.56%; N=36) of these respondents provided names of systems that were purchased and implemented at the State DOH level. For example, in Indiana the ISDH uses a system titled INEDSS. The State DOH provides access to each county for it to submit cases, document case follow up, and view county-level trends. Systems in the other states included MERLIN (Florida), PHRED (Washington), and NEDSS (Nebraska). This demonstrates that LHDs in these regions are highly dependent on the State DOH to provide the informatics systems used to view and analyze notifiable conditions. Three LHDs responded that they use Microsoft Access to store and view laboratory data.

A similar pattern with respect to the syndromic surveillance systems was observed. Of the 56 respondents, 25 (44.64%) indicated their PH agency utilized a computer system/application to view and analyze syndromic data. Of these 25 respondents, 16 provided the name of the computer system/application. Thirteen of the 16 respondents

(81.25%) provided the name of a system (e.g., ESSENCE) that was likely purchased by the State DOH but made available to SHA and LHD personnel.

The survey further measured public health perceptions of HIE as a timely and complete data source for surveillance of notifiable conditions. Sixteen representatives of public health agencies which currently exchange data with an HIE responded to this section of the survey. The perceptions of HIE as a timely and complete data source for public health are summarized in Table 19.

The respondents to these questions generally felt that ELR data made their jobs easier and supported agency efforts to improve population health. However, the respondents varied in their perceptions of the various sources of ELR data. First we examine timeliness. ELR data across the board was viewed as timely. When asked about an individual source of data, respondents generally perceived lab data as the most timely. However, when asked to compare HIE data to the other two sources (hospitals and labs), respondents generally perceived HIE data as more timely. Although inconclusive, these responses support the hypothesis that those in public health working with electronic data provided by HIEs generally consider it to be at least as timely, if not more timely, than other sources of notifiable condition data.

Respondents were also asked about the completeness of electronic laboratory data from lab, hospital, and HIE sources. The mean values for the three sources were very similar and generally equaled "Neither Agree nor Disagree" that a particular source provided complete data. When the question was asked slightly differently ("Laboratory Data are Often Missing"), then respondents tended to choose values other than "3 – Neither Agree Nor Disagree." HIE data were perceived as more often "missing" than data provided by laboratories and hospitals.

Survey Item	Mean	N
Improves Monitoring of Notifiable Conditions	4.13	15
Makes Job Easier	4.00	16
Data Available to Help Make Decisions	3.79	14
Lab Data Application Easy to Use	3.81	16
Hospital Data Timely	3.31	16
Lab Data Timely	3.88	16

HIE Data Timely	3.33	15
HIE Data More Timely Than Others	3.93	15
Hospital Data are Complete	3.06	16
Lab Data are Complete	3.00	16
HIE Data are Complete	3.20	15
Hospital Data Often Missing*	3.06	16
Lab Data Often Missing*	3.69	16
HIE Data Often Missing*	3.88	16

Table 19 – Public Health Professional Perceptions of Laboratory Systems and Data (N=16); *Indicates negatively worded item

The survey further measured public health perceptions of HIE as a timely and complete data source for syndromic surveillance. Eleven representatives of public health agencies which currently exchange data with an HIE responded to this section of the survey. The perceptions of HIE as a timely and complete data source for syndromic surveillance are summarized in Table 20.

These data reveal similar patterns to those found in the perceptions of HIE as a data source for notifiable conditions. Respondents generally felt that syndromic surveillance systems improve surveillance of emerging threats, are easy to use, and make data available to them to support decision-making.

The perceptions regarding timeliness were mixed. Separately, respondents indicated they perceived hospital-provided data as more timely than HIE-provided data. However, when asked if HIE data was more timely than other sources, respondents generally agreed.

A similar phenomenon was observed regarding respondents' perceptions of completeness. When asked if hospital and HIE data were complete, respondents generally agreed that both sources provided complete data. Respondents were slightly more likely to say that hospital data was complete. However, when the question was asked negatively, respondents generally felt that HIE data were less often "missing" than hospital data.

Perception	Mean	N
Improves Monitoring of Emerging Threats	4.45	11
Makes Job Easier	4.00	11

Data Available to Help Make Decisions	4.55	11
Syndromic Data Application Easy to Use	3.91	11
Hospital Data Timely	4.00	10
HIE Data Timely	3.63	11
HIE Data More Timely Than Others	3.72	11
Hospital Data are Complete	3.72	11
HIE Data are Complete	3.36	11
Hospital Data Often Missing*	3.27	11
HIE Data Often Missing*	2.91	11

Table 20 – Public Health Professional Perceptions of Syndromic Systems and Data

(N=11); *Indicates negatively worded item

Open-Ended Responses

Public health agency representatives were further asked to provide their opinions on the greatest potential benefits of PH involvement with an HIE. Responses were openended. Twenty-four respondents (43%) provided their thoughts. The researcher examined the open-ended responses and categorized them using a codebook developed for this study (Appendix D). The researcher then attempted to match themes from the other survey questions to the responses provided by the respondents. The major themes are summarized in Figure 13.

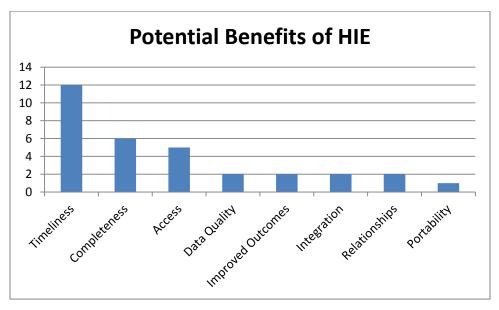


Figure 13 – Potential Benefits of HIE to Public Health Practice (N=22)

The major theme from the respondents' comments was timeliness. Respondents used phrases such as "real time," "timely reporting," and "quicker access" to describe

how HIEs might best support public health practice. A respondent from an agency currently engaged in community-based HIE activities answered like this, "The time frame is much quicker for receiving the information related to reportable diseases so that the follow-ups [sic] can be conducted quicker and more efficiently."

The next most popular theme was completeness. Respondents indicated completeness to them meant an increase in the number of case reports as well as the number of complete case reports submitted to public health. Completeness was often mentioned in the same sentence as timeliness. For example, one respondent answered in this way: the greatest potential benefit to public health practice is "the potential to receive rich, timely healthcare data sets for public health surveillance."

Access to information was also a strong theme. Several respondents reported that HIE would improve their "access to information for investigation." A number of these respondents asserted that this improved access would be "easier" or more efficient. One respondent put it this way: "Access to record level data from a number of facilities through one connection." Another dimension of access is consistency. As one respondent put it, "I currently do not receive information on a routine basis, it is hopscotch [sic] at best."

Other responses indicated that public health respondents feel that HIE can also improve the quality of the data they receive and create more integrated systems to reduce the number of data feeds and/or systems that public health agencies currently utilize. Some respondents also commented that HIE may lead to better health outcomes and relationships with providers. As one respondent put it, HIE has the potential to improve the "real time surveillance and notification of possible public health emergencies, [lead to] greater capture of cases, [lead to] more efficient use of time and staff, [and support] better health outcomes for the population."

The survey similarly asked respondents to comment on the potential challenges to greater use of HIE by public health. Twenty three respondents (41%) completed the open-ended question. The researcher examined the open-ended responses and categorized them according to common themes taken from a codebook developed for

this survey. The themes represent those used in other parts of the survey. The results of this analysis are summarized in Figure 14.

A few themes emerged from the respondents' opinions. Many respondents commented that financial resource limitations placed on public health agencies might limit greater use of HIE. For example, one respondent wrote, "Cost is also always an issue in everything we do in public health." Another respondent asserted that, "Public health doesn't have any money outside of federal funding." A third respondent noted that her LHD had previously attempted to participate in an HIE but ultimately could not join as a member "due to cost." From these responses it is clear that HIEs will have difficulty getting public health agencies to join, especially if they charge agencies membership fees. Even if fees were not charged, however, public health would still incur technical implementation and maintenance costs associated with exchanging data with the HIE. This might also be cost prohibitive to agencies given general limited budgets and "an era of budget cuts," as one respondent phrased it.

Even if financial resources are present, some respondents felt that agencies may have difficulty participating in HIEs due to human resources. Several respondents indicated that involvement in an HIE might be time intensive on staff workloads, which would be a strain on the health department. Another respondent commented that, "Learning to use the system and to teach others how to use the system if you are going to be out of the office" is a challenge. It seems that the respondents are concerned that public health agencies might not have the right labor mix and cross-training opportunities to support more automated exchange of data with clinical providers.

The final theme that emerged centered on the privacy and security of health information as it is exchanged between the HIE and the agency. One respondent asserted that, "Lack of understanding of how patient records are kept confidential and are only seen on a 'need to know' basis (this may prevent public health partners from agreeing to participate)." Other respondents questioned HIEs' ability to keep records confidential or asserted that HIEs put patient data at greater risk of misuse or breech.

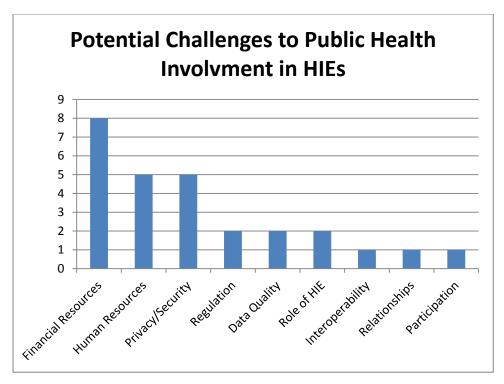


Figure 14 – Potential Challenges to Public Health Involvement in HIE Networks (N=22)

Infection Control Professionals

Sixty-three infection control professionals (IC professionals; a.k.a. Infection Preventionists or IPs) were invited via email to participate in the survey (Appendix B). Names and email addresses were gathered from the public Internet. Members of the American Professionals in Infection Control (APIC) and hospital chief information officers (CIOs) were the primary targets of the survey invitations. Each individual received an invitation to take the survey along with a link to the online survey instrument. APIC chapter leaders were asked to share the survey invite with their chapter membership. CIOs were asked to forward the survey request to the most appropriate personnel in their organization. The sample was designed to be diverse and draw a roughly equal number of participants from each state targeted in the study (Florida, Idaho, Indiana, Nebraska, New Mexico, and Washington).

Forty-four people (69.8% of the target sample) responded to the survey. Surveys were considered complete if respondents provided answers to all of the required questions even if they didn't answer all sections of the survey. Four surveys were

discarded because the respondents failed to complete all of the required questions. A fifth survey was discarded because it was completed by a hospital CIO who indicated he knew very little regarding the hospital's infection control business processes. Once these surveys were discarded, 39 complete surveys from ICPs (61.9% of the initially targeted sample) were included for analysis.

Respondents represented independent hospitals (43.6%), hospitals part of integrated delivery networks (33.3%), and integrated delivery networks (20.5%) as summarized in Figure 15. The respondents' principal roles in their organizations included the monitoring and reporting the incidence of disease to public health agencies, the planning and implementation of interventions to reduce infection, and the management of the infection control programs. Much of their time is spent every day examining, documenting, and reporting new cases of reportable diseases, multi-drug resistant organisms, and hospital acquired infections. They perform all of this while working with public health officials, hospital administrators, and clinical leaders to improve overall quality and safety for patients at their facilities.

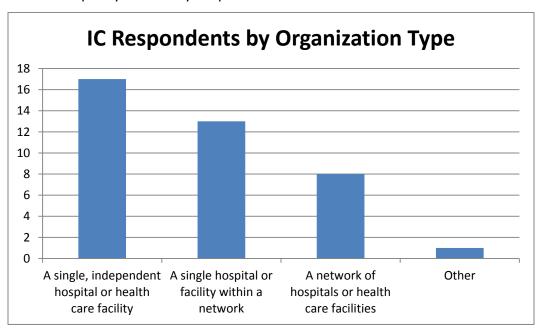


Figure 15 – IC Respondents by Organization Type (N=39)

The respondents' organizations varied widely in size. Respondents were asked to provide the number of staffed beds, average daily census, and average number of

emergency visits per day for their facility. Thirty one respondents (79.5%) provided the number of staffed beds for their respective facilities. The other two measures were more sparsely answered. The number of staffed beds ranged from 14 to 550. The mean value was 172.3 and the median value was 110. The standard deviation was high at 151.1. Figure 16 shows the distribution of respondents based on relatively equal size groups of staffed bed counts. Overall the distribution was skewed left towards organizations with fewer than 100 staffed beds. This contrasts with other surveys of hospitals where the distribution is skewed to the right in favor of larger organizations (Braun et al., 2006).

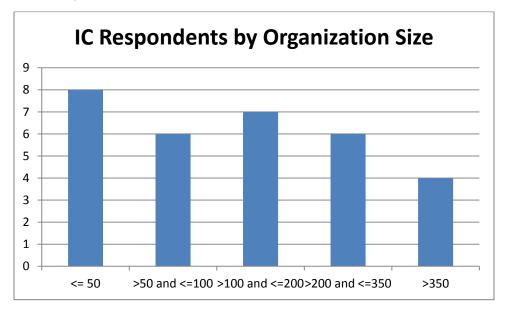


Figure 16 – IC Respondents by Organization Size (N=31); Size reflects the number of staffed beds

The IC respondents represented diverse geographic locations. Figure 17 shows the distribution of respondents by state. The majority of respondents came from the Northwest and Greater Omaha regions. This is likely due to the fact the APIC chapter leaders in those regions forwarded the email invitation out to their chapter memberships. Iowa and Wyoming are represented because they border regions touched by the APIC chapters that forwarded the invitation.

The response from Florida and Washington was sub-optimal. Although many IC professionals in these states were contacted by the researcher, the APIC chapters in these areas did not forward the invitation onto their respective chapter members.

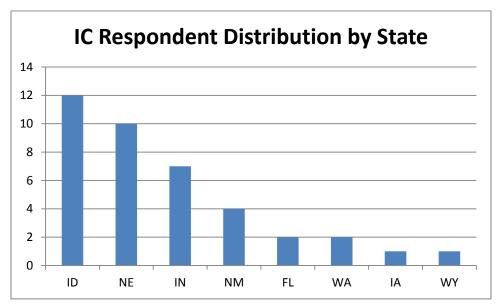


Figure 17 – IC Respondent Distribution by State (N=31)

Utilization of EHR Systems

The survey asked IC respondents to indicate whether their network or facility utilized an EHR system. Twenty eight respondents (72%) answered in the affirmative as summarized in Figure 18.

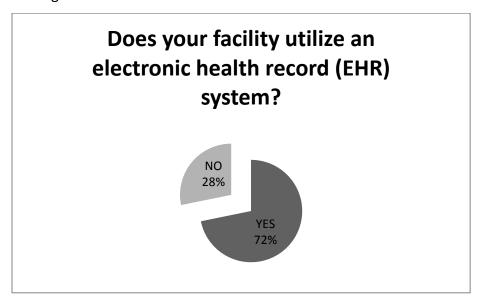


Figure 18 – Proportion of IC Respondents with and without an EHR System (N=39)

Respondents were further asked if they or an infection control colleague were asked to participate in the design, selection, or implementation of the EHR system. Only six respondents (21.4%; N=28) answered in the affirmative. One respondent indicated they were not sure whether or not infection control had been asked to participate.

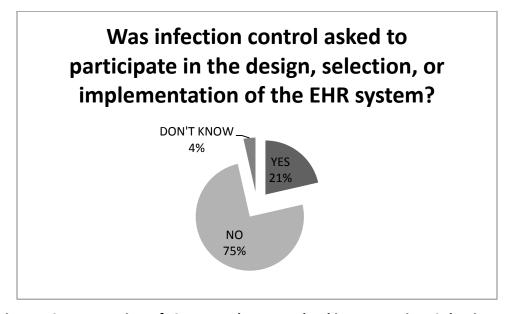


Figure 19 – Proportion of IC Respondents Involved in EHR Design, Selection, or Implementation (N=28)

Relationships and Exchange with HIEs

The survey further asked respondents to indicate whether their networks or facilities had a relationship with regional or statewide HIEs. Respondents' answers are summarized in Figure 20. Half of the respondents (48.7%) indicated they didn't know about their organization's relationship with nearby HIEs. Only four respondents (10.3%) indicated their organization was formally partnered with a nearby HIE. Four respondents (10.3%) indicated their organization had an informal relationship with nearby HIEs.

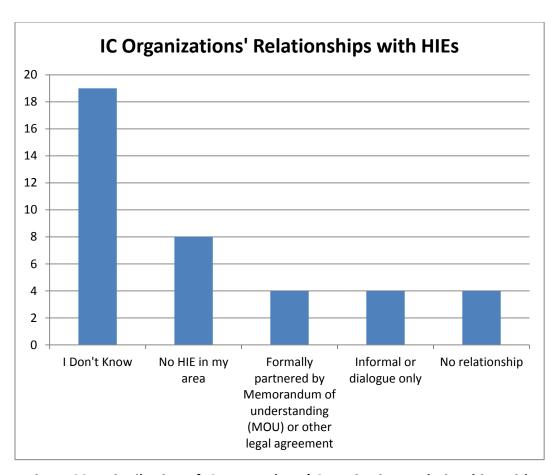


Figure 20 – Distribution of IC Respondents' Organizations Relationships with Nearby HIEs (N=39)

The survey then asked respondents if their organizations exchange clinical data with at least one HIE. The responses are summarized in Figure 21. Eight respondents (21.1%; N=38) answered in the affirmative. Another eight respondents (21.1%) answered in the negative. The remaining 22 respondents (57.9%) indicated they did not know whether or not their facility or network exchanged data with an HIE.

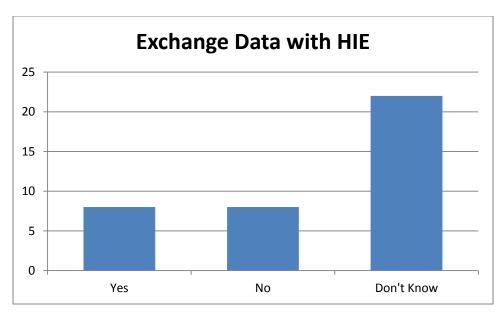


Figure 21 – IC Respondents Who Answered that their Hospital or Network

Exchanges Data with at Least One HIE

For the respondents who indicated that their organization did exchange data with an HIE, the respondents were asked to indicate if IC staff were consulted regarding the development or implementation of that data exchange. Two respondents (25%) answered in the affirmative. The other six respondents (75%) said no.

Notifiable Condition Reporting

The survey further asked respondents about their reporting behaviors associated with notifiable conditions. Thirty eight respondents answered this section of the survey. Thirty five respondents (92.1%) indicated their organizations report notifiable case information to the local health department. Twenty-three respondents (60.5%) answered that their organizations report notifiable case information to the state health agency. Only one respondent (2.6%) said their organization reports notifiable data to the CDC. Twenty respondents (52.3%) indicated that their organizations report notifiable case information to both LHDs and SHAs.

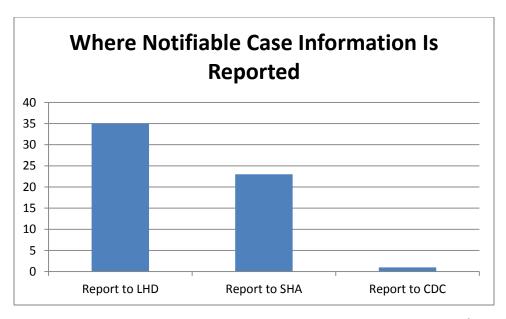


Figure 22 – Where IC Respondents Report Notifiable Case Information (N=38)

In addition to where the ICPs report notifiable case information, the survey asked ICPs to describe how the notifiable data is reported to public health. Figure 23 summarizes the various methods ICPs currently use to report notifiable case information. ICPs could choose more than one method, although most chose only one. ICPs principally print and fax information to public health. Twenty-seven respondents (71.1%) indicated this as the method (or one of the methods) used by their organization. Ten respondents (26.3%) indicated their organizations electronically fax a portion of their notifiable data to public health. Seven of the these 10 respondents indicated their organizations also print and fax in addition to electronically fax information to public health. Four respondents (10.5%) use a web-based application provided by the public health agency to enter notifiable case information to that agency. Three respondents (7.9%) reported that their facilities use ELR to report notifiable information to public health. Finally, one respondent indicated their organization reports notifiable information through an HIE.

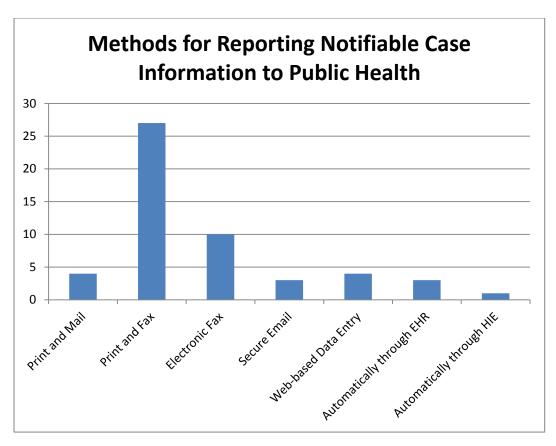


Figure 23 – IC Methods for Reporting Notifiable Case Information to Public Health (N=38)

The survey also asked respondents to estimate the average time it takes "you or your staff to review a notifiable condition case, including time to review the patient's chart, and prepare the case report for initial submission to public health." Stock responses were provided in 15 minute increments. A summary of the responses provided is in Figure 24. The distribution of responses appears normal with a third of ICPs (36.8%) answering that the average time is between 30 and 45 minutes.

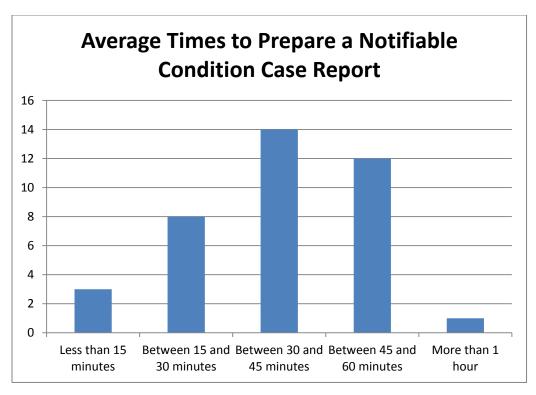


Figure 24 – Average Times to Prepare a Notifiable Condition Report (N=38)

Syndromic Information Reporting

Respondents were also asked about the reporting of syndromic surveillance information to public health. Only twenty respondents (51.3%) responded to this section of the survey. A summary of the responses provided is in Figure 25. Similar to notifiable condition information, fax is the dominant method for reporting information to public health. One IC professional commented that their organization principally uses the phone to report information to public health, although they do have access to a fax machine for sending medical record data. The phone was not an option that respondents could automatically choose from within the survey instrument.

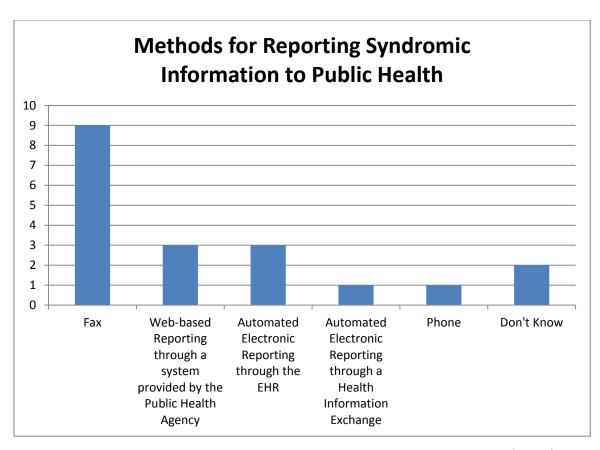


Figure 25 – Methods for Reporting Syndromic Information to Public Health (N=20)

Perceptions of EHR Systems and HIEs

The survey asked respondents to provide their perceptions of the information systems used when performing their jobs. Responses are summarized in Table 21. Responses were provided on a Likert scale, ranging from Strongly Disagree (1) to Strongly Agree (5). Higher mean scores indicate a more positive perception of the data, information, or information system — the subject of the questionnaire item. The exceptions to this are the values for the three negatively worded items. For these items, the lower the mean score the more positive the perception of the data, information, or information system. The mean scores in most cases reflect a general pattern by respondents to choose "Neither Agree Nor Disagree." Respondents overall held positive perceptions of the data and information they use and expressed satisfaction with the systems they use. However, respondents also identified they have unmet needs by these systems.

Perception	Mean	Standard Deviation	N
Data Received When Needed	3.22	1.38	36
Information Needed for Job is Available	3.11	1.31	37
Data Available to Help Make Decisions	3.54	1.17	37
Communication from PH About Community is Timely	3.81	0.97	37
Information in Computer System is Complete	2.86	1.36	36
Satisfied with Quality of EHR Data	2.91	1.13	33
Data Provided by EHR Always Accurate	3.41	1.13	32
Data in the EHR are Often Missing*	3.22	1.39	32
EHR is Easy to Use	3.44	1.13	32
Data from EHR Makes Job Easier	3.76	1.28	33
I Have Needs Unmet by EHR*	4.29	1.03	34
Satisfied with Quality of HIE Data	2.82	0.85	22
Data Provided by HIE Always Accurate	3.17	0.94	23
HIE is Easy to Use	3.22	0.90	23
Data from HIE Makes Job Easier	3.05	1.09	22
I Have Needs Unmet by HIE*	3.92	0.91	25
HIE Data More Complete	2.87	1.14	23

Table 21 – Overall IC Perceptions of EHRs and HIEs (N=39); *Indicates negatively worded item

Respondents provided answers to items related to the EHR system even if they previously indicated their facility or network did not utilize an EHR system. Therefore, a sub-analysis was performed for the set of respondents (N=28) who did indicate their facility or network utilized an EHR system. The responses are summarized in Table 22.

Perception	Mean	Standard Deviation
Data Received When Needed	3.37	1.36
Information Needed for Job is Available	3.22	1.31
Data Available to Help Make Decisions	3.70	1.20
Communication from PH About Community is Timely	3.89	0.85
Information in Computer System is Complete	2.96	1.34
Satisfied with Quality of EHR Data	2.96	1.14
Data Provided by EHR Always Accurate	3.52	1.19
Data in the EHR are Often Missing*	3.26	1.35
EHR is Easy to Use	3.56	1.12
Data from EHR Makes Job Easier	3.93	1.33
I Have Needs Unmet by EHR*	4.36	1.08

Table 22 – Perceptions from IC Respondents with EHR Systems (N=28); *Indicates negatively worded item

A similar analysis of respondents whose organizations exchange data with an HIE could not be performed because the subset of respondents was smaller than 20. The four respondents who indicated their organizations exchange data with an HIE generally provided answers that correspond to the larger group of respondents with EHR systems. There are a few notable deviations from this pattern. This group perceived communication from public health agencies as less timely and HIE data as more complete and accurate than other sources. The group further perceived their EHRs are less helpful, easy to use, and complete as the larger group of EHR users.

The researcher also looked for differences in responses based on region. Responses indeed varied by state and region as summarized in Table 23. Respondents from Nebraska were generally less positive about their EHR systems while more positive towards public health agency communication. Respondents in Washington and Idaho were generally more positive about their EHR systems. Florida and the other states were excluded from this analysis because three or less respondents from those states completed this section of the survey.

Perception	IN N=7	NE N=10	WA, ID N=14
Data Received When Needed	3.29	2.00	4.11
Information Needed for Job is Available	3.14	2.44	4.04
Data Available to Help Make Decisions	3.86	2.88	4.08
Communication from PH About Community is Timely	3.43	4.22	3.66
Information in Computer System is Complete	3.00	2.50	3.30
Satisfied with Quality of EHR Data	3.17	2.00	4.00
Data Provided by EHR Always Accurate	3.67	3.14	3.77
Data in the EHR are Often Missing*	3.33	3.38	3.18
EHR is Easy to Use	4.17	2.72	4.05
Data from EHR Makes Job Easier	3.83	3.75	4.36
I Have Needs Unmet by EHR*	4.17	4.38	4.59

Table 23 - IC Perceptions by Region; *Indicates negatively worded item

Open-Ended Responses

At the end of the survey, IC professionals were asked to comment on the "one thing that public health agencies could do to better support IC personnel in their reporting of notifiable condition and syndromic information." Thirty-one respondents provided a response to the question. The researcher examined the open-ended responses and categorized them using a codebook developed for this study (Appendix D). The researcher attempted to match themes from the other survey questions to the responses provided by the IC professionals. The major themes are summarized in Figure 26.

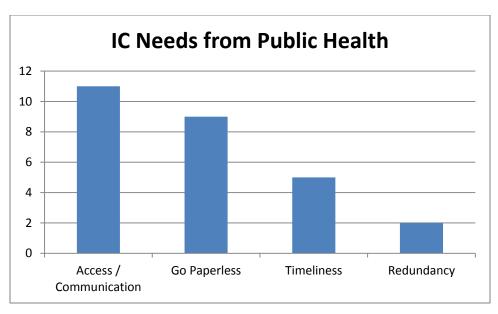


Figure 26 – Themes from IC Respondents Regarding Their Needs from Public Health

Agencies (N=31)

A major theme reflected in the IC comments was a need for better access to information and communication from public health agencies regarding situational awareness. Comments indicted that public health agencies may not adequately or efficiently share information with IC professionals about community health trends. One respondent summarized things this way: public health agencies should "report back to the hospitals the findings or at least provide a live web stream of how things are going." Several IC professionals commented that they desire up-to-date information on what's happening in their community to more effectively respond to and prevent the spread of infectious diseases. One IC respondent specifically commented on the recent H1N1 outbreak. She stated that the information coming from public health agencies was "inconsistent" during the outbreak, which caused confusion and frustration for IC professionals.

Several IC respondents suggested that public health agencies should more closely collaborate with IC professionals to share information about community health. One IC respondent specifically suggested that public health agencies make their information available online "instead of [IC professionals] waiting to receive it from the agency." Furthermore, one IC respondent suggested that beyond making information available

that PH agencies should "do something with the information that will make a difference in the prevention of infection."

Another theme was a desire by IC respondents to see public health agencies move towards paperless reporting processes. One respondent put it this way, "Right now Public Health has no EHR so we have to either call the information to them by phone or fax." Several respondents requested that agencies move reporting capabilities "on-line" so that IC professionals would no longer need to print and fax documentation.

Timeliness was also something that IC respondents desired to see public health agencies address in the future. These respondents asked first that agencies make reporting "as simple as possible" to reduce the time burden on IC personnel. Other IC respondents suggested that electronic methods for reporting would reduce the time necessary to document and submit the information to agencies. The H1N1 outbreak was mentioned as an example by one IC respondent. She stated that the additional information asked for by agencies during the outbreak, which required "case reports by hand," was "incredible [sic] inefficient."

A final theme was redundancy. Two IC respondents commented that the various reporting requirements for different public health agencies is not necessarily congruent. IC respondents asserted that LHDs and SHAs require different types of information in unique formats, requiring IC staff to sometimes enter data twice or generate multiple reports. More efficient exchange of information between agencies might address this challenge for the IC professionals.

The survey further asked IC professionals to comment on what EHR systems could do to better support the work of IC staff. Thirty one IC professionals responded to this open-ended item. The researcher examined the open-ended responses and categorized them using a codebook developed for this study. The researcher attempted to match themes from the other survey questions to the responses provided by the IC professionals. The major themes are summarized in Figure 27.

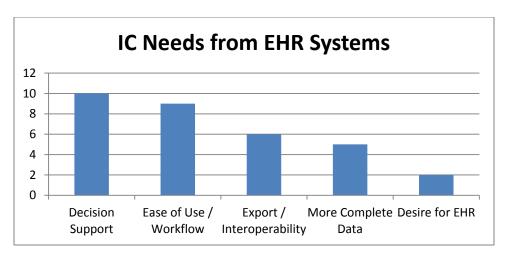


Figure 27 – Themes from IC Respondents Regarding Their Needs from EHR Systems (N=31)

The most dominant theme among IC responses was support for decision-making tasks. Respondents commented that current EHR systems and modules do not adequately support their ability to quickly or efficiently identify positive, notifiable conditions that need to be reported to public health agencies. Many responses alluded to the fact that EHR systems simply provide IC staff with the ability to access information. However, the information is not organized, streamlined, filtered, or presented in a way that supports IC workflow. From the comments received, much of the time IC professionals comb through a patient's lab results and other EHR information manually, similar to how they used to perform reviews of paper charts. Some IC respondents mentioned that they often print and hand review every laboratory information system report from the previous day.

The respondents who expressed a desire for decision support principally asked for functionality within their EHR systems to "flag reports that are questionable" and "identify potential nosocomial infections." One respondent asked for "intelligence" to "weed out" lab and other results that "don't need to be looked at." Smarter EHR systems, for these respondents, would be systems that could interpret electronic laboratory and clinical reports, find the incidence of a notifiable condition, and place the information in a queue for review by IC staff. Such functionality would address the

current challenge faced by IC professionals who today scan through screens and pages of text looking for evidence of a disease.

Another form of decision support desired by the IC respondents is EHR system functionality that "link[s] to records of patient history." Just because a lab test for sexually transmitted infection comes back positive does not mean this is the first time the patient has tested positive for that disease. Many conditions, including MRSA, VRE, and various STIs, are repeatedly tested for over the life of the patient. IC professionals desire to understand whether a MRSA exposure, for example, is new or whether it is well documented that this patient has a history of MRSA. This contextual information would help IC staff more appropriately respond to and document cases encountered.

The next dominant theme was "ease of use." Many of the comments in this category pertained specifically to a desire for faster and more efficient access to the information that IC professionals need when documenting a notifiable case. IC respondents commented that they often need to "fish" or "dig" or search (in some cases "for hours") within their current electronic systems to find the data and information they require. Several IC respondents commented that they currently look in two or more electronic systems then triangulate the information needed for the reports. One IC respondent summarized things this way: "In my opinion [the EHR] is a poor system to extract data from." Another IC respondent stated that her EHR system "require[s] an IT specialist to write a report." Instead of searching for the information they need, IC staff would like to see EHR systems that contain a module or feature that would pull information pertaining to multi-drug resistant organisms, notifiable conditions, and hospital acquired infections into a single report, view, or screen for review and action (e.g., create report, send report). One IC respondent commented that her EHR system vendor has "the tools" necessary to abstract and collate the information needed for her job, but "the cost to us to obtain that ability is cost prohibitive."

A third theme pertained to the interoperability of data and information in the EHR with other electronic systems (e.g., the web-based reporting system provided by the SHA). Several IC respondents noted that their current electronic systems do not easily

export data into a format they need for reporting to public health, CMS, and the Joint Commission. For example, comma delimited files (*.csv) and Microsoft Excel (*.xls) are popular formats used by local health departments according to a recent survey by NACCHO. One IC respondent commented that her EHR system won't export to these formats, which requires manual data entry into another computer application to complete a case report. Another IC respondent provided more general feedback, stating simply that EHR systems need to "communicate with other systems." The author assumes here that the respondent is referring to the general need in informatics for systems that interoperate with one another using standards such as HL7 and LOINC.

The fourth theme emerged from comments by IC professionals regarding the completeness of data in EHR systems. IC respondents commenting on EHR data reported that the data required for them to complete reports are often not required for entry by registration clerks, nurses, and other health professionals. One IC respondent simply asked that EHR systems "have more required fields." Another respondent requested "safeguards" to ensure "complete documentation."

The fifth theme reflects the comments of two IC respondents who requested simply to have access to EHR systems. These two respondents currently lack access to an EHR system, but both believed that having access to an electronic system would improve their workflow and ability to report information to public health.

Health Information Exchanges

Representatives from HIEs in all of the target study locations were invited to respond to a survey (Appendix C) regarding their relationships with PH agencies and support of surveillance data feeds to PH agencies. A total of 11 HIEs received invitations to participate in the survey, which included emails to six HIEs in Florida, one HIE for the state of Idaho, one HIE in Indiana, one HIE for the state of Nebraska, one HIE in New Mexico, and one HIE that spans the Washington and Idaho region. Nine individuals, representing seven HIEs (63.6% of those invited), submitted complete responses.

Five of the nine respondents were part of the HIEs' executive management team, and included chief executive officers, chief information officers, and vice-presidents of

information technology. Two of the respondents were technology development or project managers. The remaining two respondents were IT professionals, and included engineers and developers.

The survey asked the HIEs to describe their current operational state. Five of the HIEs responded that they are an "operational health information organization; transmitting data that is being used by health care stakeholders. (Ongoing revenue stream and sustainable business model.)" The remaining two HIEs answered that they are "implementing: technical, financial and legal structures are being actively developed."

HIE Relationships with LHDs

The survey asked HIEs to describe their relationships with LHDs. Responses from the seven HIEs are provided in Table 24. Two of the HIEs reported that at least one LHD fully participates in the exchange through a Memorandum of Understanding (MOU) or other legal agreement. Two of the HIEs reported that LHDs have an informal relationship with the HIE. Another two HIEs reported that the LHDs have members on working committees or the organizations' governance board. The final HIE reported that it has no relationship to LHDs in the area.

Relationship	Count (N=7)
At least one local health department fully participates through a Memorandum of Understanding (MOU) or other legal agreement	2
Informal or dialogue only	2
Board representation and committee participation	1
Public health officials participate in committees	1
No relationship	1

Table 24 – HIE Relationships to LHDs (N=7)

HIE Relationships with SHAs

The survey also asked HIEs to report their relationships with SHAs. Three of the HIEs reported that SHAs are full participants. One HIE reported that the SHA is represented on its governance board as a *de facto* member. Two HIEs reported that the relationship

to its SHA was of an informal nature. Finally, one HIE's representative indicate the relationship was unknown.

Relationship	Count (N=7)
The state health department fully participates through a Memorandum of Understanding (MOU) or other legal agreement	3
The state health department is a non-voting (de facto) member	1
Informal or dialogue only	2
Unknown	1

Table 25 – HIE Relationships to SHAs (N=7)

Exchange of Laboratory Data

The survey asked HIE representatives to indicate whether the HIE "currently or plans to exchange laboratory-based data." Five of the seven HIEs indicated the organization currently exchanges laboratory-based data. One HIE reported that it plans to exchange lab data in the future. One of the HIEs did not respond to this question.

If the HIE respondent indicated that lab data was exchanged, the survey asked a series of questions about the various electronic lab data systems available within the HIE. The survey asked if a particular type of system was simply available (e.g., operational within the IT enterprise of an organization within the HIE's area) or available and used (e.g., interfaced with the HIE and sending data). The respondents' answers are summarized in Table 26. Six HIEs reported that hospital-based laboratory information systems (LISs) are available and used within the HIE to exchange lab data. Five HIEs reported that independent regional or national (e.g., send out) labs were interfaced and exchanging data. One HIE reported that an independent lab was available but not interfaced. One HIE reported actively receiving lab data from the state PH lab. Four HIEs reported having PH labs in their area but are not currently receiving data from them. One HIE indicated it does not have a PH lab available in its region.

System	Available and Used	Available but Not Used	Not Available and Not Used
Hospital-based laboratory information system (LIS)	6		
Independent regional or national laboratory information system (LIS)	5	1	
Public health laboratory information management system (LIMS)	1	4	1

Table 26 – HIE Relationships to Lab Information Systems (N=6)

Exchange of Syndromic Data

The survey asked HIE representatives to indicate whether the HIE "currently or plans to exchange syndromic surveillance data." Two HIEs reported that they currently exchange syndromic surveillance data. Three HIEs reported that they plan to exchange syndromic surveillance data in the future. One HIE reported that it does not currently nor plans to exchange syndromic surveillance data. One HIE did not respond to this question.

If the HIE representative indicated that syndromic surveillance data was exchanged, then the survey asked about the source systems available and used within the HIE. Respondents were asked about two classes of systems that often contain syndromic data: registration systems (a.k.a. admission, discharge, and transfer or ADT) and financial management systems (e.g., claims data). The answers reported by HIE respondents are summarized in Table 27.

Five HIEs reported that they interface with and receive data from registration/ADT systems. One HIE reported that registration/ADT systems were available but not used. Only one HIE reported being interfaced with and receiving financial data. Two HIEs reported that financial/claims systems were available but not currently used. One HIE reported that financial or claims data was not available and not used.

System	Available and Used	Available but Not Used	Not Available and Not Used
Registration or Admission, Discharge, and Transfer (ADT)	5	1	
Financial management or claims system	1	2	1

Table 27 – HIE Relationships to Syndromic Information Systems (N=6)

Perceptions of Data and Public Health

The survey asked respondents about their perceptions regarding a number of aspects relevant to data exchange among hospitals, laboratories, and public health agencies in support of notifiable condition and syndromic data reporting. Respondents' answers are summarized in Table 28. The table includes answers from eight of the nine individuals who completed the survey. Individual responses are provided here instead of HIE answers, because the responses reflect personal opinion and should not be ascribed to an organization.

The first two items asked respondents to rate their overall satisfaction with existing processes for laboratory and syndromic data exchange. Responses were mixed. Some respondents seem satisfied while others are not. There were more negative responses for laboratory exchange as opposed to syndromic exchange.

The next four items pertain to timeliness. Respondents were asked whether they felt certain data providers were timely in their delivery of information to the HIE. Most respondents answered favorably, indicating they felt hospitals and labs were generally timely in their delivery of information to the HIE. This was not true, however, when the questions were phrased differently to focus on exceptions. Exceptions refer to anomalies and technical errors caused by the HL7 messages received by the HIEs. Here, several respondents answered negatively, disagreeing with statements that hospitals and labs are timely in their resolution of message errors and other exceptions.

The next two items pertain to data completeness. HIE respondents were asked to agree or disagree with statements regarding the completeness of data received from

various source systems. Several respondents disagreed with statements that asserted data from hospital and laboratory information systems are complete.

The final two items pertain to respondents' desire to increase HIE participants. Generally respondents desire to see additional labs and public health agencies participate in their respective HIEs. All but one respondent answered "strongly agree" to the statement, "I would like to see more laboratories participate in our HIE." Four respondents answered "strongly agree" to the statement, "I would like to see more public health departments participate in our HIE."

Item	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
I am satisfied with current processes for laboratory data exchange	1	2	3	2	
I am satisfied with current processes for syndromic data		1	4	2	1
Hospitals provide data to the HIE in a timely manner		1		5	2
Laboratories provide data to the HIE in a timely manner			2	4	2
Hospital message and data exceptions are handled in a timely manner by hospital interface personnel	1	2	2	2	1
Laboratory message and data exceptions are handled in a timely manner by lab interface personnel	1	1	5	1	
Laboratory messages and data received		6	1		1

from hospital information systems (HIS) and EHRs is complete and requires little transformation					
Laboratory messages and data received from independent lab LIS is complete and requires little transformation	1	3	4		
I would like to see more laboratories participate in our HIE		1			7
I would like to see more public health departments participate in our HIE			3	1	4

Table 28 – HIE Respondent Perceptions of Data Sources, Public Health, and Vendors (N=8)

Compliance with Available Standards

The survey also measured opinions concerning compliance with available health information technology standards, including messaging standards (e.g., HL7) and coding standards (e.g., LOINC). The data are summarized in Table 29 and Table 30. Respondents generally felt that vendors, hospitals, and labs were doing adequately.

First, the survey asked respondents to agree or disagree with statements concerning hospital, lab, and vendor support for available standards. Responses were generally mixed with respondents both agreeing and disagreeing to the various statements. The exception to this was the statement, "Our Hospital members support available standards to the best of their ability." For this statement, respondents either agreed or took a neutral position.

Item	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
Our Hospital members support available standards to the best of their ability			3	2	3
Our Laboratory members support available standards to the best of their ability		1	3	2	2
LIS and LIMS vendors support available standards to the best of their ability	2	2	2	2	
HIS and EHR vendors support available standards to the best of their ability	2	1	2	2	1

Table 29 – HIE Respondents' Perceptions of Standards Support (N=8)

Next the survey asked respondents to rate vendor compliance with specific messaging and coding standards. Responses again were mixed. The most popular answer across all four items was "moderate." Compliance with messaging standards like HL7 were generally rated higher than coding standards (e.g., LOINC, SNOMED).

Item	Very Poor	Poor	Moderate	Good	Very Good
How would you rate compliance by LIS and LIMS vendors with data messaging standards (e.g., HL7) for laboratory data exchange?			5	2	1
How would you rate compliance by LIS and LIMS vendors with data vocabulary standards (e.g., LOINC, SNOMED) for laboratory data exchange?	1	1	5		1
How would you rate compliance by HIS and EHR vendors with data messaging standards (e.g., HL7) for data exchange?	1	1	4	1	1
How would you rate compliance by HIS and EHR vendors with data vocabulary standards (e.g., LOINC, SNOMED) for data exchange?	2	2	3		1

Table 30 – HIE Respondents' Perceptions of Vendor Compliance with Standards (N=8)

IC Representation on HIE Board

The survey asked respondents to comment on whether the HIE had IC representation on its governance board. Results are summarized in Figure 28. Five respondents answered in the negative. Three respondents indicated they did not know whether IC professionals were represented on the board or not.

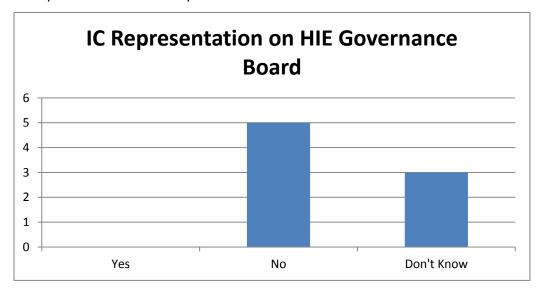


Figure 28 – IC Representation on HIE Governance Boards (N=8)

Open-Ended Responses

The survey asked open-ended questions to capture respondents' thoughts on the benefits and challenges associated with PH involvement in HIE networks. Four respondents provided their thoughts on the "greatest real or potential benefits."

Three of the four respondents provided responses that focus on benefits to public health agencies and practice. Two of these three respondents included improved timeliness in their comments. One respondent asserted that HIEs provide "infrastructures to quickly redirect resources" during an emergent public health event. The other respondent stated that public health departments "will receive...data more quickly."

Completeness was also mentioned by two of the respondents. The first respondent suggested that PH agencies could leverage HIEs to receive "a lot of information." The other respondent asserted that data would simply be "more complete."

Efficiency and costs were the final PH benefits mentioned by two respondents. The first respondent stated that PH agencies could capture increasingly more information "without the overhead of trying to maintain and implement connections to the different data sources." The other respondent suggested that PH agencies could capture more information "at lower costs."

Instead of ascribing benefits to PH agencies, one respondent suggested that providers would see the greatest benefit from PH involvement with an HIE. This respondent asserted that providers would experience, in the short term, "drastic improvement on the currently difficult paper reporting process." In the long term, this respondent felt that providers would be able to access "relevant treatment best practices" using public health data. The respondent suggested this access would be an improvement over the "current two year lag in must [sic] published research data."

The survey also asked respondents about the challenges likely to be faced as PH agencies get involved with HIEs. Six respondents provided comments. Three of the six respondents included "limited funding" or "limited resources" in their comments. These respondents suggested that public health agencies would have limited financial and human resources to partner with HIEs. One of these respondents noted that the resource deficiency was not only in terms of dollars and time but also capacity and knowledge. This respondent commented that public health agencies might have difficulty in handling "the amount of information that is available" in an HIE.

Two respondents commented that the pace of public health agency adoption of HIE would be slow. One respondent suggested that "bureaucracy" would make progress hard to achieve. The other respondent noted that, "public health is a large entity that does not move as fast as the private sector."

Another respondent suggested that public health agencies might be challenged to "determine the information that is valuable for public health needs." This respondent asserts that agencies should carefully review the available data from an HIE, assess the data's characteristics, and consider data use as agencies become more regular consumers of HIE data.

One respondent commented that public health's use of HIE information should be done cautiously to prevent what the respondent described as the "Crying Sheep" phenomenon. This respondent asserted that public health agencies over-hyped the threat of H1N1 in 2009 and "pushed" swine flu shots onto the public. This respondent suggests that public health agencies not use early evidence from HIEs to dominate "control of public airwaves" for, in his words, "non-threatening conditions."

A final respondent commented that public agencies should avoid a "go it alone" attitude. This respondent asserted that the CDC and other public health agencies should cooperate with larger, national HIE and health IT initiatives led by other public entities such as ONC and CMS.

Discussion

Public health surveillance processes require "timely, accurate, and complete" data (Lombardo & Buckeridge, 2007, p. 266). A mixed methods study comprehensively captured and analyzed clinical data from hospitals and laboratories concomitantly with survey data from public health, infection control, and HIE professionals to examine the real and perceived value of the completeness, timeliness, and usefulness of data from HIEs used in public health surveillance processes. Study results demonstrate that HIE-enhanced data to public health processes are and are perceived to be complete, timely, and useful. The results further suggest that, despite adding value to surveillance processes, there are tangible barriers to greater use of HIE-enhanced data by public health agencies. Finally, the results imply that HIE-enhanced data may have value to important stakeholders involved in surveillance processes but work outside of public health agencies. In the rest of this section, the results of the study and their implications for HIEs, public health agencies, and surveillance processes are discussed.

Completeness

When asked to identify potential benefits of HIEs, more complete data and disease reports was a dominant theme in public health professionals' responses (see Figure 13). The survey also measured public health professionals' attitudes towards existing HIE-provided notifiable and syndromic data (see Table 19 and Table 20), and respondents generally answered that HIE-provided data was at least as complete as, and sometimes more complete than, data from other sources. Thus the ability of HIEs to improve data completeness is thought to be a reality for some, and HIE data is perceived to be capable of improving completeness for others.

Clinical data, however, are heterogeneous within and across data sources, information systems, and states. Assessing the completeness of a single communicable disease report (CDR) or ELR message is therefore difficult, because two identical "scores" could very well represent two very different sets of data. In this study, a novel approach to evaluating completeness was utilized. Completeness profiles for real-world data sets, were constructed, and the values reflected the heterogeneity found in health

care data while allowing comparisons across data sets. Each profile contained the list of possible data elements in the set and the completeness of each element, which allows data sets to be compared to one another, field by field, and measured against a set of objective standards. Sets of reportable results from two states were compared, and raw data from one state was compared to HIE-enhanced data from the other state. Such comparisons allow informatics and public health researchers to better understand the nature and characteristics of surveillance data, and they allow for the development of future strategies to improve surveillance data quality and public health practice.

There are several nearly equivalent fields in the Indiana and Wisconsin data sets (see Table 11). Fields that identify the patient to whom the clinical data belong, patient identifier, patient name, patient date of birth and gender, vary by roughly one percentage point. Test name, which identifies the test performed by the laboratory, was 100% complete in both data sets. Status of the test result, which indicates whether the result is preliminary or final, was 99.5% complete in both data sets. The likely reason why these fields are 100% complete or nearly 100% complete and similar across the two sets is that these values are required data elements in HL7 messages. Patient identifier and patient name are required fields in the PID segment; test name and status of test result are required fields within the OBX segment. Patient date of birth and gender are not required fields. However, patients are routinely asked for these data, and health information systems routinely capture these data for identification and care delivery processes.

For fields that are not required by the HL7 messaging standard but considered to be useful to public health surveillance processes, both data sets are less complete, and there is wide variability. With respect to information about the patient to whom the clinical data belongs, date of birth and gender are the only fields that are close to 100% complete. Information that would readily allow public health officials to contact a patient is provided less often. The Indiana data more often have a phone number for the patient, whereas the Wisconsin data are more likely to have an address. Race and

ethnicity are also less frequently available from ELR messages, especially ethnicity which is available for less than 20% of patients.

Low completion rates for patient information inhibits the ability of public health officials from adequately performing surveillance and response activities. For example, public health agencies routinely contact patients who test positive for a sexually transmitted infection (STI). Controlling the spread of STIs involves counseling the patient to inform his or her sexual partners about the test result and methods to keep sexual partners safe. However, without address and phone information, public health agencies need alternative strategies for contacting the patient. This often involves contacting the physician, nurse, clinic, or hospital to obtain the additional information needed. These phone calls and additional data lookups seem inefficient when the various electronic systems that capture this information could be integrated and leveraged to provide more complete data to public health.

Likewise, low completeness for race and ethnicity prohibits accurate tracking of disparities in disease burden. Society expects public health agencies to examine patterns of disease by race and ethnicity and address disparities. However, ELR data streams may be unusable as a source for health disparities monitoring since it is present less than 20% of the time. Some data senders within the INPC, for example, record race and ethnicity data when patients register at the clinic or hospital. However, they do not forward that information to the lab, so when the ELR message is generated this field is null. This is an important clinical workflow characteristic important for public health and informatics professionals to understand when considering how to optimize data capture and reporting of notifiable disease surveillance data.

The fields that describe the ordering provider also varied in their rates of completeness. The INPC data set contains information on the provider name, address, and phone number roughly two-thirds, three-fourths, and five-eighths of the time respectively. The Wisconsin SHA data set contains provider information more than 90% of the time. The researcher examined the most prevalent values in these fields to better understand why the data sets varied.

Data senders in the INPC transmit the name of patients' health care providers in several fields, including the OBR-16 (Ordering Provider), PV1-7 (Attending Doctor), PV1-8 (Referring Doctor), PV1-9 (Consulting Doctor), and PV1-17 (Admitting Doctor). In the WDHS data set, the name of the provider is only transmitted in the OBR-16 field. A review of the INPC messages in which provider names are missing revealed that most of these messages originated from two data sources: a national reference lab and a local county health department. These sources provide a large portion of the INPC's lead exposure data, and the messages contain rich detail about the lead tests, results, and However, the tests rarely provide information about the ordering the patients. provider. When a value is in the OBR-16 field, the value is simply a name. Most INPC facilities provide an identifier along with the name (e.g., a National Provider Identifier, local staff id number). There were 2,511 (15.3%) messages in the INPC data set from these two sources. Only a third of these messages contain a provider name; none of which could be matched to the INPC Master Provider Index. If a match had occurred, then the INPC would have populated the STF-3 field with the provider's name and staff id number. Potentially the INPC could work with these data sources to improve completeness of provider information to nearly 80%, which would be a significant improvement.

Similarly, the fields containing provider addresses and telephone numbers varied between the data sets. Data senders in the INPC use only the OBR-17 (Callback Number) when they transmit a phone number. INPC senders do not transmit address information. Therefore the INPC must resolve provider addresses and phone numbers from its Master Provider Index, a registry of individuals known to the HIE. The INPC scans the several provider name fields (e.g., OBR-16, PV1-7) and matches the identity data to the information in the index. Resolved identities are used to populate the STF (Staff) segment fields with phone and address data. WDHS data senders use the ORC segment to transmit provider addresses and phone numbers. The fields include ORC-23 (Ordering Facility Name), ORC-24 (Ordering Facility Address), ORC-25 (Ordering Facility Phone Number), and ORC-26 (Ordering Provider Address).

The WDHS provider address and phone numbers are more complete than the equivalent INPC fields. To understand the likely reasons for this difference, the researcher examined the most prevalent values and discussed organizational practices with representatives from the INPC and WDHS. Both the INPC and WDHS address data appear to represent mailing addresses for clinics, physician offices, and hospitals. WDHS phone numbers also appear to represent main phone lines for large clinics and medical centers. The INPC phone numbers, on the other hand, appear to represent more clinical departments (e.g., Internal Medicine) rather than main switchboards. These values appear to be reflective of their sources. The WDHS phone numbers, contained in the Ordering Facility Phone Number field, did appear to represent the facility where the lab test order was placed. The INPC data come from the HIE's manually curated index where employees of the HIE are provided with departmental staff lists and contact information from the hospitals and medical centers.

Although the INPC provider address and phone number fields are less complete than the equivalent WDHS fields, these fields in the INPC "reportable" messages are dramatically more complete than provider address and phone number fields in the "raw" messages from hospitals and labs. When messages first arrive at the INPC, none of them contain provider address information, and only 0.15% of messages contain provider phone numbers (see Table 7). The INPC's data cleansing and normalization routines improve the completeness of these fields by 84.6% and 73.2% respectively (see Table 12). Enhancement is accomplished by matching the provider identity information in the messages to the INPC's Master Provider Index, which results in a dramatic improvement. These values, however, do not approach 100%, and they likely won't reach 100%. Many of the provider identification fields contain values such as "99999^Emergency Services" or "NOT ASSIGNED^MD," indicating that the test was ordered by house staff. Since these values do not represent an individual person, these values are not resolved by the INPC's Master Provider Index, which prevents resolution of a staff member address and phone number. One possibility is for the INPC to resolve these organizational roles to mailing addresses and switchboard numbers similar to the WDHS messages. While this would improve completeness, the values would not reach 100%. Reaching 100% completeness is unlikely given that: a) interns and house staff at teaching facilities turn over on a regular basis; and b) clinicians start new practices or move between practices routinely.

Provider information is important to public health agencies, which often need to contact the patient's provider to follow up on the report of a notifiable condition. Missing information could delay timely response to disease outbreak. When information is missing, public health professionals are likely to call the main number of the organization or a department. It may take a few extra minutes, phone transfers, voicemails, or keystrokes to correctly identify the provider who treated the patient.

More accurate, detailed information about the provider who ordered the test may be something to address in the future. However, like race and ethnicity, details about the individual clinician caring for the patient is not of high value to other clinicians who later view the lab result. The test name, test result, and organization name are often sufficient for clinical workflows in which the test result is accessed and used to make treatment and health management decisions. For example, a primary care physician is unlikely to need the name of the physician in the emergency department who ordered the MRSA culture. This aspect of clinical workflow is important to understand when considering strategies to potentially improve the completeness of these fields.

The fields corresponding to the test performed by the lab also varied in their completeness. Units of measure, normal range, specimen source, and abnormal flag fields varied greatly between the Indiana and Wisconsin data sets (see Table 11). These are optional fields according to the HL7 messaging standard, although they have proven to be useful in public health surveillance processes. The INPC messages have low rates of completeness for these fields; the rates were 17.5%, 18.3%, and 28.4% respectively. Fields from WDHS messages are more complete than the Indiana messages, but the rates of completeness are not as high as other fields within the WDHS messages. The exception to this is the specimen source field, which does contain details about the source of the specimen (e.g., blood, urine) in more than 90% of messages.

A likely reason that both data sets have few values in these fields is that many notifiable condition tests (e.g., cultures) are interpreted using qualitative methods and do not have numeric results. Units of measure and normal range fields are meaningless in these cases. However, for specimen source and abnormal flag fields, the WDHS data do appear to be more complete. A review of the INPC messages revealed that data senders tend to report values that should be in these fields in an NTE segment, which is a free text note appended to the end of the OBX segment. Although this method does not violate HL7 compliance, it does not meet the intent of the HL7 standard. Messages would be more easily computed if these data elements were in the designated HL7 field.

The inconsistencies and heterogeneity described in this study are important to take into consideration when developing applications that receive and interpret ELR messages. Furthermore, it should be noted that the heterogeneous data described in this study were received from modern health IT systems, transmitted to public health between 2007 and 2010. Overhage et al. (2001) previously described the general problem of heterogeneous data in health care. The findings from this study support the earlier studies on this subject and demonstrate that health care data heterogeneity remains an important factor when solving public health problems using informatics approaches, despite the use of upgraded and newer IT systems by health care providers in Indiana and Wisconsin. Newer systems do not impact, by default, the nature and characteristics of the data captured by clinicians for health care delivery processes.

Furthermore, the fields that were found to be most complete are those that align with HL7 messaging requirements and clinical information flows. Data elements designated as required in specific HL7 segments (e.g., patient name) were almost always present. Likewise, data that are provided to downstream health IT systems, which can be reported back upstream to public health, were typically present. Interestingly, not all of the data elements identified in state administrative code were available through ELR messages. This was observed even in the Wisconsin data set which generally possessed greater completeness. Therefore, updating administrative codes (changing policy) to

require reporting of certain data elements may not be sufficient to improve the completeness of ELR messages.

If data elements are routinely captured by EHR system components upstream from the lab information system (LIS), then HIEs can play a supporting role to enhance lab messages as they are communicated from providers to public health agencies. For example, the INPC can resolve certain data elements like clinician addresses and telephone numbers from non-lab data feeds and information systems to which the HIE has access. Enhancement may not be possible if the HIE fails to receive the data elements needed by public health, or the data are not routinely captured for use in health care delivery (e.g., ethnicity). Public health agencies, HIEs, and clinical providers will need to work together to implement solutions to the challenges of incomplete data.

Timeliness

Timeliness was the most commonly mentioned potential benefit of public health agency involvement in HIEs when public health professionals' were surveyed (see Figure 13). It was also a major theme in the comments provided by infection control professionals (see Figure 26). Responses from public health professionals to more narrowly worded questions about the timeliness of HIE data were more varied (see Table 19 and Table 20). Some public health officials felt that HIE data were more timely than other sources like labs and hospitals; other respondents perceived HIE data to be just as timely as the other sources. Furthermore, these results do not appear to vary based on respondent location or health department size. Such variation is inconclusive; however, it does support the argument that HIE-supplied surveillance data is at least as timely as electronic data reported from other sources.

Timeliness of HIE data was not measured empirically in this study. A primary reason for not measuring timeliness is the existing evidence in the literature that direct ELR and ELR through an HIE are timely methods for electronically providing data to public health agencies (Effler et al., 1999; Nguyen et al., 2007; Overhage et al., 2008; Panackal et al., 2002; Wurtz & Cameron, 2005). One of these studies focused on data from the INPC (Overhage et al., 2008). The study demonstrated that ELR data delivered through the

INPC were more timely for 13 of 16 notifiable conditions than spontaneous reports submitted through traditional channels to a local health department. Average time lags between delivery of the ELR data and receipt of the spontaneous reports ranged from 1.2 days to 20.0 days. Given this study involving the INPC and additional evidence in the literature that ELR is a timely method for reporting notifiable disease information to public health, timeliness of the INPC messages was excluded from this study.

Usefulness

The study further examined the usefulness of data provided to surveillances processes from an HIE. Stakeholders involved in surveillance processes perceived HIEs as useful, which is evidenced by the fact that public health professionals identified integration of systems and interoperability as likely benefits to greater use of HIEs by public health agencies (see Figure 13). It is further evidenced by infection control professionals' comments that greater use of electronic systems could improve their work practices, including reducing the amount of redundant work to complete multiple reports to various public health agencies (see Figure 27).

In addition to perceived usefulness, the study empirically measured the ability of HIE-enhanced data to improve interoperability. Many perceive interoperability to enable disparate systems to "talk to one another." However, the value of interoperability also involves improving the semantic meaning of the data transmitted in standardized messages to public health agencies. Semantic meaning refers to how well the content of a field or series of fields can be understood by the information system or application reading the message. Semantic enhancement of messages is valuable, because while a field may contain a data value other than NULL, the value in that field might be anything but useful to public health surveillance procedures. For example, the OBX-3 test identifier may contain a value like "CULT^CULTURE^SMLAB" and the OBX-5 test result may contain a value "FEW." The test name and result pair provides virtually no detail on the organism for which the culture was performed. After translating the message, the INPC provides public health with the standardized LOINC code 6462-6 (Bacteria identified in Wound by Culture) as a mapped value for the OBX-3 field. In

addition, the NCD appends a new OBX segment to the message with a value "54217-5^"Public health notifiable condition^LN" in the OBX-3 field and the value "Coccidioidomycosis" in the OBX-5 field. These enhancements add semantic meaning to the message, enabling public health agency information systems and epidemiologists to quickly interpret which organism was found and the method used to confirm the presence of the organism.

Unfortunately the semantic meaning of the raw, incoming tests from hospitals and labs is often difficult to discern quickly for humans or computers. Only 3,724 (<0.01%) of the raw messages from the INPC contain standardized LOINC test identifiers in the OBX-3 field. Similarly, none of the "original" messages in the WDHS data set contain a standardized LOINC test name or identifier. After enhancement, the number of LOINC-encoded test identifiers improved by 426.9% (from 19,228 to 101,305) for the messages processed through the Regenstrief NCD. Similarly, the WDHS messages translated using the PHIL software all contain LOINC-encoded test identifiers.

Semantic meaning of the OBX-5, test result value, field was also examined. Here the enhancements were fewer but still notable. A very small fraction of the raw INPC messages contained SNOMED-encoded test results. For WDHS messages, 8,612 (12.3%) of the OBX-5 fields for which there were coded observations contain SNOMED codes. The rest were encoded using local codes and descriptions. The INPC does not currently map OBX-5 values to the SNOMED terminology. The WDHS' partner does map OBX-5 values to SNOMED. The number of SNOMED-encoded concepts improved 14.6% (from 8,612 to 9,868) in the "phil" message set.

Beyond improving the messages' ability to be more easily interpreted by epidemiologists and information systems in public health agencies, semantically interoperable data also improve public health capacity to track disease incidence and share their knowledge with other public health agencies. At the national level, the CDC maintains a list of LOINC and SNOMED codes that represent notifiable condition disease tests and organisms (http://www.cdc.gov/NEDSS/DataModels/index.html). If SHAs and LHDs tracked disease incidence using the standardized vocabulary codes, then all three

levels of public health could seamlessly report, aggregate, and monitor disease information. Standardized approaches could further drive faster public health action on emerging threats. For example, it may be desirable to immediately address incoming cases of meningococcal disease over those of gonorrhea. Standardized reporting would cut down on the time it takes to identify the test results and begin case report follow-up and management.

In addition, LOINC and SNOMED could be provided in messages from public health agencies to clinical information systems to enhance decision support at the bedside. For example, a localized outbreak of salmonella might prompt local health officials to request that providers order stool cultures to better track the spread of the disease. If the message contained a specific request for more "20955-1^Salmonella Stl Cult" tests, then EHR systems could resolve that value to tests available in their local vocabularies, and the specificity and actionable nature of the request may support greater acceptance of the request from public health by clinicians in practice. Lurio et al. (2010) provide additional examples of this kind of decision support.

Value of HIE to Public Health Surveillance

The results therefore demonstrate that data supplied and enhanced by HIEs is perceived to be and can be more complete, timely, and useful that data transmitted directly from hospitals and laboratories. However, the WDHS data suggest that HIEs may not be necessary to ensure complete, timely, and useful data for surveillance processes. The WDHS data, for example, are more complete in the sense they populate more of the constituent parts of HL7 messages than the INPC data. Moreover electronic reporting of lab data, independent of an HIE, have been demonstrated to be more timely than spontaneous reporting. Further, WDHS is able to semantically enhance the data using the Atlas Public Health PHIL software component. These data indicate that HIEs like the INPC aren't necessary and that public health agencies should possibly consider an approach involving direct connections to hospital and laboratory information systems using vendor software to clean and enhance data as it is received.

Concluding that public health agencies are better off without HIEs using these arguments, however, may be nearsighted and fail to factor in other benefits beyond completeness, timeliness, and usefulness. First, although the WDHS data were generally more complete, there may be reasons for this completeness unexplained by the data in this study. When asked about the high completeness of the data, a member of the Atlas Public Health team stated that Wisconsin was the first state health agency to purchase software from Atlas Public Health. Therefore it is possible that, under pressure to make the project a clear success story for the company, the implementation team pushed hard on data senders to ensure complete ELR messages. Furthermore, the WDHS may conduct independent validation of data feeds and require that messages are well populated before turning on a live data feed. Many state health departments do this.

Second, with respect to usefulness, the PHIL component may be able to improve semantic interoperability, but the tool may not be that helpful with maintenance and upkeep of LOINC and SNOMED mappings over time. Vreeman et al. (2008) have demonstrated that hospitals and labs frequently update their catalogues and coding systems. Keeping tables that hold local-to-standard code mappings up-to-date, given the frequency with which data senders add new or modify existing codes, is challenging. In addition to local mapping tables, the CDC also periodically updates its master files that identify LOINC and SNOMED notifiable disease test and organism codes, which would require maintenance and upkeep at the local or state health department level (S. Grannis & Vreeman, 2010).

When implementing the PHIL software as part of the Atlas Public Health PHIN Suite, the implementation team from Atlas will assist the health department to map laboratory catalogues to LOINC. However, post-implementation it becomes the health department's responsibility to keep the mapping tables up to date. Furthermore, PHIL does not automatically update is core reference list of available LOINC and SNOMED codes. The help file in PHIL shows users how to manually add a new LOINC or SNOMED code to the core set. The software does not have an auto-update feature.

This information provides further evidence that HIE-enhanced data add value to public health surveillance processes. By partnering with HIEs, public health agencies can improve the usefulness of surveillance data and leverage community assets to be efficient and cost-effective. HIEs often assume the role of central mapper and arbiter of local-to-standard vocabularies for their participants. The INPC has historically supported its participants in translating their local codes to LOINC, namely because INPC participants' vendors did not support transmission of LOINC codes. Other HIEs have also played this role (Porter, Starmer, King, & Frisse, 2007). The data in this study demonstrate that raw messages straight from vendor EHR and LIS systems very rarely contain LOINC codes, so the need to initially map and keep the mapping tables up-todate remains. A model where LHDs and SHAs nationally take on the responsibility of maintaining mapping tables would likely duplicate effort and waste limited financial and human resources. Since HIEs are often required to keep mapping tables up-to-date to enable semantically interoperable exchange between clinical partners, HIEs can provide value to public health surveillance processes by leveraging their mapping efforts to deliver ELR messages with standardized values. This approach is likely to be more cost effective for public health agencies, even though costs were not measured in this study. Furthermore, this approach leverages community-based infrastructure and resources. Public health survey respondents perceived HIEs as a way to access data "through one connection" rather than multiple connections to every provider in the jurisdiction.

Finally, HIEs have the capacity to do more than just receive and enhance one-way data streams from clinical systems to public health information systems. HIEs also have the capacity to provide two-way communication between providers and public health agencies, and HIEs can be partners to improve relationships between clinical providers and public health professionals. Both services would add value to surveillance processes.

Bi-Directional Communication

When asked what public health agencies could do to better support infection control professionals, survey respondents predominantly stated they desired enhanced communication from public health agencies concerning situational awareness. Survey responses revealed that most health departments share community-level information with their partners via electronic newsletters and other forms of static reporting (see Figure 12). The existing methods proved to be slow and frustrating for some infection control respondents during the H1N1 outbreak, according to comments in the survey. Infection control professionals asked in the survey to explore different communication modalities with agencies, including real-time Web feeds of data, to receive up-to-date information on disease outbreaks and other threats to public health in their communities.

Better reporting of information back to providers has been referred as bi-directional communication (Magruder, 2010). Bi-directional communication supports situational awareness where providers in the community are kept up-to-date on current outbreaks and syndromic events. The CDC has funded several recent initiatives to improve bi-directional communication, and HIEs have been involved in some of those efforts (Dobbs et al., 2010; Gamache et al., 2010). HIEs could be leveraged to provide infection control professionals with knowledge about current public health events in the community. Secure messages could be sent in real-time to infection control workstations, or the HIE could host a secure wiki or portal that would provide the current trends in notifiable disease and syndromic counts for the community. Engagement of HIEs in initiatives like Health Alert Networks (HANs) might also be something for HIE and public health leaders to consider (Baker & Porter, 2005).

Relationships

Building stronger relationships with health care providers and the community was another minor theme from public health professionals' comments on the potential benefits to public health practice (see Figure 13). Public health has a desire and need to foster strong working relationships with health care providers. Many public health

professionals see these relationships as necessary to effectively collect the data and information required for public health reporting, and they further view these relationships as partnerships to address population health issues. The responses from infection control professionals provide further evidence that both sides of the public health reporting process desire strong working relationships. While a few IC professionals stated that they have a "great working relationship" with the local health agencies, more respondents indicated that these relationships could be improved (see Figure 26).

Relationship building is something that HIEs do. In Indiana, public health professionals are engaged in the governance of the HIE, and the HIE has partnered with public health on a number of innovative surveillance practice improvements (S. J. Grannis et al., 2010). One of these improvements centered on the development of a mechanism to improve bi-directional communication between public health and physician practices (Gamache et al., 2010). HIEs at their core have a fundamental interest in building strong relationships between health providers to develop trust in the exchange of clinical data across organizational boundaries. HIEs could work to foster trust and collaboration between public health and health care stakeholders. The INPC has been successful in doing this, and there is an opportunity for other communities where HIEs are in development to forge strong relationships and improve surveillance processes.

Challenges to HIE Enhancement of Public Health Surveillance

Despite evidence and strong perceptions of HIEs adding value to public health surveillance, few of the public health agencies surveyed are currently exchanging data with an HIE. Only one in four public health professionals who responded to the survey indicated any kind of formal relationship between their public health agency and a nearby HIE. When asked if the public health agency exchanged clinical data with a nearby HIE, slightly less than one in three respondents answered in the affirmative. Similarly, three in seven HIEs indicated that public health agencies were full partners in the exchange.

The evidence of public health involvement with HIEs from this study supports similar evidence from an early 2007 survey by Hessler et al. (2009). The previous survey found that 40 percent of public health agencies and 35 percent of HIEs reported formal relationships between agencies and an HIE. Given the similar results in this study, it appears that the aims and funding in the ARRA legislation of increasing HIE adoption and electronic reporting of notifiable conditions have had little effect on the relationships between public health and HIE to date. To achieve the aims of ARRA and realize the full value that HIE can bring to public health surveillance, more engagement in HIEs by public health agencies will be necessary.

The lack of public health engagement with HIEs does not appear to be predicated on negative perceptions of HIEs. When asked about their perceptions of HIEs, most public health professionals responded quite favorably towards public health involvement and exchange of data with HIEs. Public health professionals whose agencies are already engaged in HIE data exchange generally held more positive views of HIEs, yet the perceptions of those in agencies disengaged from HIEs did not differ all that greatly. Open-ended responses from public health respondents confirm that most public health professionals see HIEs as positive organizations that should partner with and provide services to the respondents' agencies.

Although HIEs are viewed positively, there are real barriers to greater use of HIEs to improve public health surveillance. First, there are few operational HIEs able to partner and exchange data with public health agencies. Second, limited resources in public health agencies limit agency engagement and exchange with HIEs. Finally, some public health professionals fear that the risks to privacy and security might outweigh the benefits to surveillance. Fortunately, these barriers can be surmounted in the future through relationship building and collaboration.

Limited Number of Operational HIEs

A major challenge to greater exchange of data between public health agencies and HIEs is the limited number of operational HIEs across the U.S. There are an estimated 193 initiatives across the U.S. pursuing HIE activities (eHealth Initiative, 2009). Previous

research has shown that despite great interest in HIEs, few initiatives are mature, operational HIEs actively exchanging clinical data (Overhage et al., 2005). In this study, five of the seven HIEs reported that they were operational. This proportion is estimated to be much higher than the general population of HIEs across the U.S. Most HIE initiatives are either implementing technologies or in the planning stages. Few active HIEs will initially limit the ability of public health agencies to begin exchanging surveillance data with HIE participants. However, as more HIEs are implemented and achieve operational status, greater public health use of HIE networks will be a possibility. For now, public health agencies and HIEs should form informal relationships to ensure surveillance services and infrastructures can be appropriately planned and leveraged in the future.

Financial and Human Resources

When asked about potential challenges to greater public health involvement in HIEs, survey respondents overwhelmingly indicated that resource constraints are their top concern. Some of the comments from public health professionals indicated that HIEs either do or could require substantial financial costs to enable public health participation. In fact, one respondent indicated that her agency had attempted to formally participate with a local HIE but could not afford the fees assessed to the agency. Other comments suggest that public health is always concerned about costs because of limited funding generally for public health programs. This may be especially true during the timeframe in which respondents completed the survey as a number of state legislatures and the U.S. Government were looking at ways to trim public spending. Going forward, HIEs will need to work with public health agencies to define and maintain a delicate balance between affordability and functionality. Thus far HIE has not been proposed as a public resource that is to be fully funded by government and available to all for use at no cost. HIEs must develop and implement sustainability plans to pay for ongoing maintenance and operations of their infrastructures and services. Most HIEs are not-for-profit corporations so the likely business model will involve participants sharing in the overall costs for HIE development, maintenance, and

operations. Such a model would require public health agencies to pay for the services they use within the HIE, although it does not mean that HIEs should view public health as an endless stream of revenue. HIEs will need to find models that charge public health fair and equitable rates for service utilization while recognizing that many public health agencies are dependent on public funds which can be at times unstable given economic and political forces.

In addition to financial resource constraints, survey respondents indicated that public health agencies have human resource constraints. The literature has described a general lack of human capacity for informatics in public health agencies (American Medical Informatics Association, 2008; Hersh, 2010). The comments in this survey reflect the larger industry concern for a viable public health informatics workforce. Limited human resources results in many projects that would be great to do if the few informatics staff at the agency had additional time. For greater adoption and use of HIEs in public health, HIEs and agencies will need to work collaboratively to determine how to leverage one another's human resources to create and support interfaces among disparate clinical systems that have the potential to supply surveillance processes with complete, timely, and useful data.

Trust in HIE Data Exchange

Public health agency trust in HIE privacy and security practices is a final challenge to greater support and enhancement of surveillance by HIEs. Public health respondents to the survey indicated that privacy and security were potential barriers to greater PH-HIE partnerships (see Figure 14). The comments from these respondents suggested that public health officials and professionals may lack an understanding of how HIEs manage the privacy and security of protected health information. In Indiana, the INPC is a business associate of the health care provider members, and the HIE manages strong technical and physical safeguards to ensure that health information is only provided to an authorized user (e.g., legitimate physician) in an authorized context (e.g., patient is currently under the care of that physician). Health agencies only receive patient-level

information for those notifiable conditions which, according to state law, are required to be reported. Other HIEs likely have similar protections in place.

For public health agencies to trust HIE networks to use patient information in appropriate ways and maintain the privacy and security of the information, agencies and HIE networks will need to create legal frameworks for trust (Gravely & Whaley, 2009). This process will require agencies and HIEs to articulate the privacy, security, and confidentiality obligations that go above and beyond the Health Insurance Portability and Accountability Act of 1996. The frameworks will establish a baseline of trust that each partner will respect and protect the patient information entrusted to it. Over time, stronger trust should develop as public health agencies and HIEs demonstrate their ability to keep patient information private and secure as information is shared for surveillance purposes.

Establishing a baseline of trust may not be easy. It may require HIEs to educate public health agencies as to their privacy, security, and confidentiality practices. HIEs should be transparent about their practices for keeping patient information safe and private. Agencies should, in turn, discuss their practices and work with HIEs to develop the legal framework. If there are still concerns, then the scope of the exchange could be initially narrowed to demonstrate effectiveness. Once the narrowly scoped exchange is in place and additional trust is developed, then additional data and information might be shared and an expanded legal framework established. Trust and greater exchange of data will be necessary for HIEs to fully support agencies in improving surveillance.

Capacity for HIEs to Add Value to Surveillance Beyond Reporting to Public Health

The study, and much of the discussion to this point, focused on the value that HIEs do and can provide to public health agency surveillance processes. However, the study results further suggest possible value that HIEs can add to surveillance processes beyond the walls and systems of public health agencies. Data from the survey of infection control professionals suggest that HIEs have the potential to support and enhance the surveillance responsibilities of IC departments and staff. Infection control professionals play an important role in the collection and reporting of surveillance data

to public health agencies. These professionals further play an important role in the development, implementation, and evaluation of interventions to reduce the spread of disease and improve patient outcomes.

Unfortunately infection control professionals spend a large portion of their time on manual, inefficient processes when collecting and reporting data to public health. Survey data from IC professionals demonstrate that the dominant method for reporting case information from hospitals is fax (see Figure 23), with many IC professionals printing information before faxing it to the health department. Other responses and comments from IC professionals in the survey confirm that IC workflow is often inefficient and redundant. For example, slightly more than half of the IC respondents reported that their hospitals are asked to report notifiable disease information to both local and state health agencies.

In addition, IC professionals are asked to create internal reports for hospital administrators from various departments. In some instances, IC professionals further report notifiable disease information directly to the CDC. At one hospital in Indianapolis, the IC manager commented that her team consists of 0.5 full-time equivalents devoted strictly to completing the variety of reports needed by local, state, and federal health agencies. To complete their various reports, IC staff use a wide range of information programs and systems. For example, the local health department in Indianapolis asks that information be provided using Microsoft Excel worksheets while the state health agency and CDC ask that information be submitted using two, disparate online reporting systems.

Redundancy in reporting, and the variety of reporting mechanisms, is extremely inefficient. In a national survey of IC professionals by the Association of Prevention in Infection Control (APIC), respondents indicated that redundancy in reporting to public health prevents IC staff from performing their other job duties, including organizational surveillance, infection control interventions, and disease prevention strategies (APIC, 2009). The APIC study further reported that IC departments within hospitals are critically understaffed, which presents an opportunity for HIE to broadly support and

enhance surveillance activities by reducing redundancy and improving IC capacity. One service the HIE could provide is standard outbound feeds of data to IC staff in the various formats required by local, state and federal agencies. Since HIEs generally serve a defined geographic area, the number of templates needed would be small (perhaps on the order of 3-10). The templates would be populated by leveraging the data exchanged by HIE participants (e.g., labs, hospitals). IC professionals could use their local EHR system or a portal from the HIE to review the data, make corrections or additions as necessary, and route the final reports to the various health agencies. A service to support reporting would benefit from the data enhancements available from the HIE, and it could leverage the existing legal agreements and data feeds between the hospital and the HIE. Reducing workload on IC staff would enhance department capacity by freeing IC professionals to focus on other important tasks including development and implementation of effective IC interventions and strategies.

Infection control professionals further indicated in the survey that their current information systems lack decision support for routine IC functions. Comments on the survey suggest that IC professionals desire functionality from their EHR, or another system like an HIE, to flag ELR reports that are questionable and identify likely nosocomial infections. These comments support evidence from APIC, which reported only one in five (20%) IC professionals have "data-mining programs" or electronic surveillance systems that allow for the identification and investigation of potential infection in real time (APIC, 2009). This often results in IC professionals spending significant portions of their work day combing through ELR reports to determine whether or not a notifiable disease was present in a culture and should therefore be reported to public health (Dixon, Stamper, & Cutshall, 2007).

Services from HIEs, like the Regenstrief NCD, could be used to provide IC professionals with decision support. For example, the HIE could implement rules to identify and flag ELR messages for potentially reportable results. Infection control professionals could review the flagged reports in their local EHR or via a central portal hosted by the HIE. The HIE might also provide a service that helps IC staff distinguish

hospital acquired from community acquired diseases like MRSA (Kho, Lemmon, Dexter, & Doebbeling, 2008). Another service could involve providing IC staff access to aggregate-level and trend data on diseases reported to public health by the collective membership of the HIE. There are likely a wide range of services that HIEs could potentially provide IC professionals.

HIE support for IC professionals would be an additional way for HIE to broadly support public health surveillance processes. Few IC professionals, however, are engaged in HIEs or their organizations' HIE activities. Survey data show that half of the respondents indicated they did not know whether their organization participated in an HIE (see Figure 20). Furthermore, none of the HIEs surveyed indicated that their governance boards contain IC representation (see Figure 28). Other responses from the IC professionals (see Figure 18) show that nearly three out of four IC facilities utilize EHR systems. The presence of EHR systems suggests the capacity for the IC respondents' facilities to participate in an HIE. In a future with more HIEs and greater adoption and use of EHR systems, HIEs should collaborate with the IC departments from their membership, vendors, and public health agencies to explore services to support IC professionals and workflow.

Limitations

There are several limitations to the study which caution against over-generalizing the conclusions. First, the study principally analyzed the value of HIE to public health surveillance in the context of electronic laboratory reporting. Electronic laboratory data and data flows to public health were a major focus for this study. However, laboratory data represent only a portion of the total data and information used in public health agencies for surveillance of notifiable conditions. In addition to laboratories, many states also require hospitals and physicians to report notifiable disease case information to public health officials. Public health professionals collate the various data into a comprehensive case report which drives public health workflow processes. To provide a more thorough evaluation of the data completeness of notifiable condition data to public health, it would be necessary to create and analyze completeness profiles for

data received from physician offices, hospitals, schools, and other sources of notifiable disease information.

This study further based its conclusions on data provided by a survey of public health, infection control, and health information exchange professionals in select states. While the surveys possessed very good response rates, the survey data may not be representative of the entire U.S. population of these professional groups. Opinions and surveillance processes in other regions of the U.S. might vary from those reported by Furthermore, the survey respondents were not selected randomly. this sample. Respondents self-selected to participate in the study. The study data may overrepresent those who are advocates of HIEs. In addition, very few respondents to the survey reported active engagement with an HIE, which translates into practical experience working with HIE-enhanced data. This should caution readers from overgeneralizing the opinions regarding HIE. Finally, the survey instruments were pilot tested, but they were not validated. Validation of the instruments is recommended before use in other studies. Moreover, validation of the survey instruments and study data is highly recommended before any policy decisions might be made by health departments or HIEs.

Conclusion

A health information exchange (HIE) can add value to public health surveillance processes. This research demonstrates that data from an HIE are at least as complete, timely, and useful as electronic data submitted directly from clinical information systems. In some instances, HIE data are more complete, timely, and useful. HIEs also have the capacity to add value to public health surveillance through two-way communication, development of stronger relationships between agencies and clinical providers, and services for infection control practitioners. However, despite their potential value, few HIEs are actively exchanging data with public health agencies to support and improve surveillance processes. HIE sustainability, limited public health agency resources, and a lack of trust are three important barriers to greater exchange of data between HIEs and public health agencies.

The findings from this research have implications for future public health informatics research, the evolution of clinical and public health information systems, as well as public policies that impact clinical providers and public health agencies. First, the evidence in this study suggests future directions for public health informatics research. The "minimum data set" for surveillance data completeness developed for this project was created *de novo*, because there is limited knowledge regarding information needs of those involved in surveillance processes. While the minimum data set can be used to measure and monitor completeness of surveillance data in Indiana, its applicability in other states is unknown. Future research in public health informatics should capture additional data on surveillance information needs. By better understanding information needs, researchers will be able to triangulate a standard data set for measuring and comparing completeness, as well as other aspects of surveillance data quality, across states and regions. A single standard will further enable the establishment of benchmarks for measuring and comparing surveillance processes, data, and systems.

The creation of a standard surveillance data set should also involve the public health informatics community to ensure the end product is consensus-based. Recent efforts by the CDC to develop surveillance data sets have included a limited number of

participants. As researchers triangulate additional data on information needs, the public health informatics community – CDC, SHAs, and member groups like the International Society for Disease Surveillance (ISDS) – should meaningfully discuss the creation and adoption of a consensus-based minimum data set for use in surveillance processes. In addition to use in future research, a widely accepted standard for surveillance will enable local and state health departments to evaluate potential data sources and monitor existing data sources for changes in completeness, timeliness, usefulness, and other dimensions of surveillance data quality. The newly formed Joint Public Health Informatics Taskforce could support the alignment of efforts across member groups and public health agencies, catalyzing research on information needs to create and maintain a consensus-based surveillance data set applicable across agencies, states, and surveillance processes.

The evidence from this study further suggests a need for additional research on the information needs of infection control preventionists. These individuals are critical to the reporting, monitoring, and prevention of infectious disease in health care delivery organizations. Yet the evidence from the survey suggests that these professionals often lack decision support as well as the ability to quickly identify and report data to public health agencies. Future studies should gather detailed evidence on the data that ICPs need and use in practice as well as the information systems to which they have access. Research should also carefully observe ICP practice, noting common practices, standards, and workarounds associated with seeking, interpreting, applying, and sharing information in the course of their daily activities.

The evidence from ICP studies could be applied to the development, implementation, and adoption of new technologies to support IC practice. Although survey respondents requested decision support from their EHR systems, another approach would be to leverage HIE services and infrastructure to enhance ICP workflow. Modules within EHR and HIE systems could be developed and evaluated to measure impact on IC practices, standards, and workarounds. Evaluation studies could also compare EHR and HIE approaches to supporting IC practice. Furthermore, services and

support beyond notifiable disease surveillance should also be explored. IC professionals could benefit from a range of support including identification of community acquired infections, hospital acquired infections, and surgical site infections. Technologies and services to support IC practice are likely to enhance not only public health surveillance processes but also improve the ability of IC professionals to perform their other responsibilities. All of these anticipated impacts should be carefully measured as the technologies are deployed and evaluated *in situ* across multiple hospitals and other settings.

This study also has implications for clinical providers and information systems that exchange data with public health agencies. The analysis of HL7 messages revealed that many reports of notifiable disease are missing key data needed by public health agencies for surveillance processes. While HIEs have the capacity to improve the completeness of ELR messages, HIEs will be unlikely to improve the completeness of every message or key data field if clinical providers are not capturing and exchanging the key data elements with HIEs. Data elements like race, ethnicity, physician phone number, and patient phone number need to be regularly captured by electronic systems. This implies data entry by a clinician, registration clerk, or other human resource in the health care system. Data however are captured for a specific purpose, and the collection of additional data elements is costly. Additional data elements require staff to ask for and then record the information, which translates into additional time and labor. Care providers, HIEs, and public health agencies will need to carefully balance surveillance process needs with the costs of additional data entry. Integration of information systems, leveraging common HIE infrastructure, can provide methods for enabling more complete reports while minimizing costs. However some providers may be required to collect additional data if their current methods only record certain data elements on paper rather than in a different clinical information system.

In addition to missing data, this study identified weak adoption of standard terminologies by clinical information systems. The use of LOINC and SNOMED CT was very limited among the source systems in both Indiana and Wisconsin. Although many

efforts have been made to encourage and incentivize clinical information system vendors and users to adopt standard terminologies for routine data exchange, there remains a reliance on local terminologies and coding systems. While HIEs can support the process of mapping local codes to standard terminology concepts, this research suggests more work is required to achieve the long term vision of native support for standard terminologies. Recent public policies, such as the American Recovery and Reinvestment Act of 2009, aim to incentivize the exchange of standard clinical terminologies. However, these policies emphasize standards during the testing and certification of clinical information systems. Future research is necessary to monitor the adoption and use of standard terminologies in practice.

Evidence from this study further suggests the importance of master provider indices to HIEs in the enhancement of surveillance processes. Many HIEs concentrate their efforts on the development of master patient indices to appropriately link clinical data for a given patient across multiple clinical encounters. This study suggests that patient indices are important, because they can enable HIEs to enhance ELR messages as they flow from clinical information systems to public health surveillance systems. Future research should measure the impact of patient linkages on the enhancement of data elements like patient phone number and address. However, the study also suggests that master provider indices are equally important to enhance the data in ELR messages that pertain to the clinicians treating the patient for an infectious disease. This evidence implies that future studies could more fully describe and measure the impact of provider linkages on the completeness of provider data. Moreover, future studies examining multiple HIEs and their use of or capacity for a master provider index would enhance knowledge around data linkage and its importance to surveillance processes and other HIE services.

Finally, the evidence in this study has implications for public policy. Investment and momentum from the American Recovery and Reinvestment Act of 2009 provides an opportunity to address some of the barriers facing HIEs and public health agencies. The latest data from the Healthcare Information Management Systems Society indicates that

44% of hospitals are likely to achieve Stage 1 of meaningful use (HIMSS, 2011). Two of the menu set criteria for achieving "meaningful use" ask hospitals and physician practices to utilize ELR and syndromic surveillance methods to electronically submit data to public health agencies, and several of the core criteria encourage hospitals and physicians to participate in an HIE. ARRA further provides funding to each state to establish or expand HIEs for exchanging clinical data across the continuum of care. The legislation also provides funding for connecting HIEs and statewide networks, forming a nationwide infrastructure that will include federal agencies including the CDC (Social Security Administration, 2010; Trustees of Indiana University, 2010). Since the passage of ARRA, HIEs have seen an increase in interest from clinical providers to exchange clinical data. This presents an opportunity for public health agencies and HIEs to collaborate on improving surveillance processes. The collaboration could build relationships and trust between HIEs and public health agencies as they work together to solve a common goal.

In addition to trust, meaningful use may create opportunities to address the barriers of public health resources and HIE sustainability. Unfortunately the ARRA legislation provides very little direct funding to public health agencies to enhance their information systems, personnel, or operations to support meaningful use objectives. Since the passage of ARRA, however, budget allocations and additional legislation have attempted to increase resources for public health to enable receipt and processing of new ELR and syndromic data feeds. For example, the CDC recently awarded a \$5 million grant from its surveillance budget to increase electronic reporting from 500 hospitals, 100 of which are to be critical access or rural hospitals (Conn, 2011). HHS further announced that up to \$137 million would be available during the next fiscal year for public health agency infrastructure improvements, in part to support meaningful use (Department of Health & Human Services, 2011). HIEs are also likely to benefit from ARRA and related funding to develop and implement infrastructure and services to meet provider and public health agency needs. This investment presents HIEs an opportunity to implement solutions that should be sustainable in the future. HIEs need to think strategically about

their infrastructure investments to create services that add value and support a range of common HIE functions which can be leveraged to support additional public health, provider, and other participant needs.

Ultimately HIE networks will make significant contributions to public health surveillance processes and provide an infrastructure to enhance public health decisions and policies while improving population health. The findings from this study demonstrate the value that HIEs do and can have for improving surveillance processes. ARRA and subsequent initiatives are driving adoption of infrastructure and components that are likely to mitigate current barriers and create a national infrastructure for improved population health surveillance and monitoring. Additional research, collaboration, and hard work will be necessary to create and sustain value to public health surveillance processes as well as the underlying people, processes, and technologies that support these processes.

Appendix A

Survey of Public Health Professionals

Public Health Stakeholders

1. Welcome and Introduction

Dear Public Health Professional,

Public health agencies protect the health and safety of populations. A key function of public health agencies is surveillance or the ongoing, systematic collection, analysis, interpretation, and dissemination of data about health-related events. Recent public health events, such as the H1N1 outbreak, have renewed interest in and attention towards the improvement and sustainability of public health agencies' capacity for surveillance activities.

This survey was designed to capture public health professionals' knowledge and attitudes towards existing surveillance processes and information systems. The survey asks a number of questions about the information systems used in your agency or department that capture, analyze, and report surveillance data. The survey also asks questions about health information exchange organizations that are expanding their capabilities to facilitate exchange of surveillance data.

We thank you in advance for providing anonymous, honest answers regarding the surveillance systems you use.

This survey was developed and is being administered by a PhD student at Indiana University-Purdue University Indianapolis (IUPUI). All questions and concerns should be directed to Brian Dixon (bedixon@iupui.edu).

Please note that no record-level or identifying data will be released without prior consent. Aggregate findings will be included in the student's thesis, peer-reviewed publications, and presentations at conferences. Findings may also be shared with organizations such as the Centers for Disease Control and Prevention (CDC), the National Association of County and City Health Officials (NACCHO), and the Association of State and Territorial Health Officials (ASTHO).

This survey has been approved by the IUPUI/Clarian Institutional Research Board (IRB), Study No. EX1010-24.

Public Health Stakeholders
2. Information about You
Please begin the survey by providing some information about yourself and your role within the public health agency.
1. How would you characterize your role within the agency?
Epidemiologist
Executive Management
Information Technology Professional
Other (please specify)
2. How long have you been at the agency?
Less than one year
1-2 years
2-3 years
3-5 years
5-10 years
10+ years
3. How would you describe your use of computers?
None – I prefer not to use computers, and when I do I find it difficult to get anything done.
Basic – I can use the computer to complete most tasks necessary for my job, but I rarely do anything with computers that I've not been shown how to do.
Average – I use the computer to complete tasks necessary for my job, and I occasionally play games, read news stories, pay bills, and/or purchase goods with the computer.
Advanced – I use the computer at work and home for many things, like reading news stories, playing games, and/or paying bills. I also consider myself handy with computers, doing things like installing new hardware (e.g., extra hard drive), configuring my home network, and burning CDs or DVDs.
Expert – I tend to not only use the computer for many things but also build, fix, and/or program computers at work and/or home.

Public Health Stakeholders
3. Information about Your Organization
Please provide information about your public health agency or department.
* 4. What jurisdiction does your health agency or department cover?
The United States
Individual State
Individual County
Individual City
City-County (Metro area)
Other (please specify)
5. What is the size of the population that this health department serves?
<25,000
25,000 - 49,999
50,000 - 99,999
100,000 - 249,999
250,000 - 499,999
500,000 - 999,999
1,000,000+
* 6. What is the location of your public health agency?
City/Town:
State:
* 7. Is your agency part of a Health Alert Network (HAN) with other local and/or state
public health agencies?
Yes
○ No
O I don't know

Public Health Stakeholders
4. Relationship to Nearby Health Information Exchanges
Please provide information regarding your health department's / agency's relationship with any nearby health information exchange organizations.
* 8. How do you best characterize the relationship between your health agency or department and regional/statewide health information exchange (HIE) organizations?
An HIE organization is defined as an organized entity, often a legal corporation, that specializes in facilitating electronic exchange of clinical and administrative health care data among a diverse group of often competing health care institutions, providers, and data repositories.
No HIE in my area
No relationship
Informal or dialogue only
Formally partnered by Memorandum of understanding (MOU) or other legal agreement
Non-voting (de facto) member
Other (please specify)

Public Health Stakeholders		
5. Current Data Exchange with Nearby HIE		
* 9. Are you currently exchanging data with an HIE?		
Yes		
○ No		
Onn't Know		
Not Applicable		

Public Health Sta	akeholders
6. Current Surveil	lance Data Receipt (Lab)
whether your agency/depa	rtain to your agency's / department's receipt of laboratory-based data. If you are not sure rtment receives this type of data, please proceed to the next page.
	or this survey are defined as those diseases (illnesses, conditions) that are either required to be reported by state y states to the CDC for public health surveillance activities.
	ur agency or department currently receive/access laboratory-based ble conditions? Choose ALL that apply.
Notes: These rep	orts may be submitted by the lab or health care provider.
Postal Mail	
Facsimile	
Electronic Mail	
Web-based Reporting	g System
Electronic Laboratory	Reporting (ELR) from Hospitals to System at Health Dept.
Electronic Laboratory	Reporting (ELR) from Laboratories to System at Health Dept.
Electronic Laboratory	Reporting (ELR) from Health Information Exchanges to System at Health Dept.
Don't Know	
	the approximate breakdown (using percentages) for each method of
receiving/access	ing lab-based reports of notifiable conditions. The values should total
100.	
% Postal Mail	
% Fax	
% Email	
% Web-based Reporting System	
% ELR from Hospitals	
% ELR from Laboratories	
% ELR from HIEs	

7. Current Surveillance Data Receipt (Syndromic)	
The following questions pertain to your agency's / department's receipt of syndromic data. If you are not sure whether your agency/department receives this type of data, please proceed to the next page.	
Note: Syndromic Data for this survey are defined as those data elements (e.g., chief complaint, number of school absentees) reported as initial manifestations of disease before clinical diagnosis has been confirmed.	
12. How does your agency or department currently receive/access syndromic data?	
Choose ALL that apply.	
Postal Mail	
Facsimile	
Electronic Mail	
Web-based Reporting System	
Electronic Reporting (e.g., automated data exchange) from Hospitals to System at Health Dept.	
Electronic Reporting (e.g., automated data exchange) from HIEs to System at Health Dept.	
Don't Know	
13. Please enter the approximate breakdown (using percentages) for each method of	
submitting syndromic data. The values should total 100.	
% Postal Mail	
% Fax	
% Email	
% Web-based Reporting	
System % Electronic Reporting	
from Hospitals	
% Electronic Reporting	
from HIEs	

Public Health Stakeholders
8. Current Surveillance Data Exchange
Please describe whether and how your agency or department shares laboratory and/or syndromic surveillance data and information relevant to your jurisdiction.
14. With which organizations does your agency or department routinely share surveillance data? Choose ALL that apply.
Media Reporters
Health Care Providers in My Region/State
Local Health Departments in My Region/State
My State Department of Health
State Departments of Health in My Region
U.S. Centers for Disease Control and Prevention
World Health Organization
Other (please specify)
15. Which methods does your agency/department use for sharing data? Choose ALL
that apply.
Printed Letters or Newsletters via Postal Mail
Electronic Newsletters via Email
Web-based Reporting via Manual Data Entry
Automated Electronic Messages via the Public Health Information Network Messaging System (PHIN MS)
Automated Electronic Messages via the Nationwide Health Information Network (NHIN)
16. Which method is used most often by your agency/department?
Printed Letters or Newsletters via Postal Mail
Electronic Newsletters via Email
Web-based Reporting via Manual Data Entry
Automated Electronic Messages via the Public Health Information Network Messaging System (PHIN MS)
Automated Electronic Messages via the Nationwide Health Information Network (NHIN)

Public Health Stakeholders
9. Laboratory Surveillance: Information Systems and Usage
Public health agencies use a variety of computer systems and applications to monitor the health of populations. We would like to understand your use of the various systems and applications in use at your agency. In this section, we will ask a variety of questions about the systems and applications you use and your interactions with those systems.
* 17. Does your agency or department use one or more computer systems or applications
to view and/or analyze laboratory-reported data for notifiable conditions, regardless of
whether your health department or some other entity (e.g., the state health department)
developed it?
Yes
○ No
* 18. Do you use the computer systems or applications to view laboratory-reported data for notifiable conditions?
Yes
○ No

Laboratory Surveillance	e: Information Systems and Usage
ollowing questions relate to your us ed data for notifiable conditions.	se of the computer system(s) or application(s) to view and/or analyze labor
9. What is the name of the	computer system or application that you use to view or data for notifiable conditions?
0. How often are the data in	n the system or application updated?
Several times per hour	
Several times per day	
Several times per week	
Several times per month	
About once a month	
I don't know	
Other (please specify)	

Puh	lic H	lealth	Stal	cehol	Idere
I WD				VOI IO	

11. Laboratory Surveillance: Information Systems and Usage (cont.)

21. The following list contains features common in computer systems and applications that allow access to laboratory-reported data for notifiable conditions. Please indicate the extent to which they are available to you (e.g., does the feature exist in the system?).

If a feature is unavailable to you, check "This feature is not available."

	This feature is available	This feature is not available	this feature is available
Alerts when a certain disease are reported or incidence of a specific disease exceeds "normal" levels	\bigcirc	\bigcirc	\bigcirc
Export or extract data from this system to another system or application	\bigcirc	\bigcirc	
Geographical Information System (GIS) views (e.g., ability to view lab reports by zip code or census tract)		\circ	
Influenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring	\bigcirc	\bigcirc	
Patient demographics – ability to view the patient's contact information (e.g., phone no.)	Ō	Ō	Ō
Patient-level health information (e.g., access to the patient's electronic medical records)	\bigcirc	\bigcirc	\bigcirc
Patient-level vital signs (e.g., body temperature)			
Provider demographics – ability to view provider contact information (e.g., practice phone no.)			
Trend data based on disease or jurisdiction			
Track patients who receive care outside of the jurisdiction	Ŏ	Ŏ	Ŏ
View or search for data based on custom parameters (e.g., name of disease, serotype)			
View or search for data based on custom patient characteristics (e.g., age group)	\circ	\bigcirc	
View or search for data based on custom time period (e.g., last month, from 1/1/2007 to 12/15/2008)	\bigcirc	\bigcirc	\bigcirc
View full reports from the reporting laboratories	\bigcirc		\bigcirc
Generates reports with summary statistics (e.g., number of new cases reported) that can be shared within your agency to manage workflow	Ō	Ō	Ō
Automatically sends summary reports in email or as email attachments to staff within the agency	\bigcirc	\bigcirc	\bigcirc
Integrated with the Health Alert Network (HAN) whereby alerts can be easily disseminated to other public health agencies and the medical community	\bigcirc	\bigcirc	\bigcirc

If a feature is not available to you, please skip to the ne	I do not use the	I use the feature	I use the fea
	feature	some of the time	time
Alerts when a certain disease are reported or incidence of a specific disease exceeds "normal" levels	\bigcirc	\circ	\circ
Export or extract data from this system to another system or application	\bigcirc	\bigcirc	
Geographical Information System (GIS) views (e.g., ability to view lab reports by zip code or census tract)	\bigcirc	\bigcirc	\bigcirc
Influenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring	\circ	\bigcirc	
Patient demographics – ability to view the patient's contact information (e.g., phone no.)	Ö	Ō	O
Patient-level health information (e.g., access to the patient's electronic medical records)	\bigcirc	\bigcirc	\bigcirc
Patient-level vital signs (e.g., body temperature)			
Provider demographics – ability to view provider contact information (e.g., practice phone no.)			
Trend data based on disease or jurisdiction			
Track patients who receive care outside of the jurisdiction	\circ	\bigcirc	
View or search for data based on custom parameters (e.g., name of disease, serotype)	Ō	Ō	
View or search for data based on custom patient characteristics (e.g., age group)	$\tilde{\bigcirc}$	$\tilde{\bigcirc}$	$\overline{\bigcirc}$
View or search for data based on custom time period (e.g., last month, from 1/1/2007 to 12/15/2008)	Ŏ	Ŏ	Ŏ
View full reports from the reporting laboratories	\bigcirc	\bigcirc	
Generates reports with summary statistics (e.g., number of new cases reported) that can be shared within your agency to manage workflow		Ō	
Automatically sends summary reports in email or as email attachments to staff within the agency	\bigcirc	\bigcirc	\bigcirc
Integrated with the Health Alert Network (HAN) whereby alerts can be easily disseminated to other public health agencies and the medical community	\bigcirc	\bigcirc	\bigcirc

Public Health Stakeholders

13. Laboratory Surveillance: System Perceptions

Please take a moment to think about the application or computer system you use most to interact with laboratory surveillance data (e.g., laboratory-confirmed incidence of notifiable conditions). The following questions are in relation to this application or system.

23. Please indicate your level of agreement or disagreement with each of the following statements.

statements.						
	StronglyN Agree	Moderately Agree	Nor	Disagree	/Strongly Disagree/	Not Applicable
Data from laboratories are often missing, which requires me to look for it elsewhere (e.g., paper chart, phone, fax, email)	\bigcirc		Disagree		\bigcirc	\bigcirc
The format in which I receive laboratory-provided data meets my needs	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Data from hospitals are often missing, which requires me to look for it elsewhere (e.g., paper chart, phone, fax, email)	Ŏ	Ŏ	Ŏ	Ŏ	Ŏ	Ŏ
The system enhances our ability to monitor the health of our community	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The data received is always accurate		\bigcirc	\bigcirc	\bigcirc		\bigcirc
The data are easy to integrate into my other applications and reports	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
My work load has increased since I started using the system		\bigcirc	\bigcirc	\bigcirc	\bigcirc	
The format in which I receive hospital-provided data meets my needs	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
It is easy to use the system	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information received from laboratories is timely	Ó	Ŏ	0	Ó	Ŏ	O
Data from the HIE are often missing, which requires me to look for it elsewhere (e.g., paper chart, phone, fax, email)	0	\circ	0	0	O	0
The information provided by the HIE(s) is timely	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The system enhances our relationships with health care providers	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I am satisfied with the quality of the data I am receiving	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information from laboratories is complete	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The data available to me help me make decisions	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The data and information I use is rarely incorrect		\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information provided by the HIE(s) is more timely than the information received directly from healthcare providers (e.g., hospitals, laboratories)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	0	\bigcirc
I rarely need to correct the data received from hospitals	\bigcirc	O	\bigcirc	O	\bigcirc	O
The information from the HIE is complete	\bigcirc	\circ	\bigcirc	\circ	\circ	\bigcirc
I rarely need to correct the data received from HIEs	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The format in which I receive HIE-provided data meets my needs	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information from hospitals is complete	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information received from hospitals is timely	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I have needs that are not being met by the system	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The laboratory-reported information is available when I need it	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Recent changes incorporated into the system enhanced its effectiveness	0	\bigcirc	\bigcirc	\bigcirc	0	\bigcirc

I receive laboratory-reported data when I need it The change in workflow required by the system has been problematic The system improves the detection and management of notifiable conditions The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public The system improves the detection and management of emerging threats to public threats the system improves the system improves the system improves the system improves the s	in I need it	arely need to cor	rect the data receive	from laboratories		\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	
	e system has been problematic O O O O O O O O O O O O O O O O O O O	eceive laboratory	reported data when	I need it		\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	
	and management of notifiable conditions OOO OOO OOO OOO OOO OOO OOO OOO OOO O	e change in work	flow required by the	system has been proble	ematic	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\subset
	and management of emerging threats to public	e system improv	es the detection and	management of notifia	ble conditions	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\subset
	nd management of emerging threats to public \(\)	e system makes	my job easier			Ŏ	Ŏ	Ŏ	Ŏ	Ŏ	Č
			es the detection and	management of emerg	ing threats to public	Ŏ	Ŏ	Ŏ	Ŏ	Ŏ	Č

Public Health Stakeholders
14. Syndromic Surveillance: Information Systems and Usage
Now we will ask similar questions about the computer systems and applications used in your agency or department to process and review syndromic surveillance data.
* 24. Does your health agency or department use an electronic syndromic surveillance system regardless of whether your health department or some other entity (e.g., the state health department) developed it?
Yes No
* 25. Do you use the syndromic surveillance system?
Yes
○ No

Public Health Stakeholders
15. Syndromic Surveillance: Information Systems and Usage
26. What is the name of the system or application that you use to view syndromic surveillance data?
27. How often are the data in the system or application updated?
Several times per hour
Several times per day
Several times per week
Several times per month
About once a month
I don't know
Other (please specify)

If a feature is unavailable to you, check "This feature is not available." This feature is not available. This feature is not available. This feature is not available available available available available available available available available available. Alerts when certain data categories are reported or a specific category exceeds "normal" levels Export or extract data from this system to another system or application Geographical Information System (GIS) views (e.g., ability to view lab reports by zip code or census tract) Influenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring Patient demographics – ability to view patient contact information (e.g., phone no.) Patient-level health information (e.g., access to the patient's electronic medical records) Patient-level vital signs (e.g., body temperature) Provider demographics – ability to view provider contact information (e.g., practice phone no.) Trend data based on syndrome, category, or jurisdiction Track patients who receive care outside of the jurisdiction View or search for data based on custom patient characteristics (e.g., age group) View or search for data based on custom patient characteristics (e.g., age group) View or search for data based on custom patient characteristics (e.g., age group) View or search for data based on custom patient characteristics (e.g., age group) Output 12/15/2008) Generates reports with summary statistics (e.g., number of new cases reported) that can be shared within your agency to manage workflow Automatically sends summary reports in email or as email attachments to staff within the agency	If a feature is unavailable to you shock "This feature	ro is not sus!!s	hlo "					
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Provider demographics – ability to view provider contact information (e.g., practice phone no.) Trend data based on syndrome, category, or jurisdiction Track patients who receive care outside of the jurisdiction View or search for data based on custom parameters (e.g., chief complaint, diagnosis) View or search for data based on custom patient characteristics (e.g., age group) View or search for data based on custom time period (e.g., last month, from 1/1/2007 to 12/15/2008) Generates reports with summary statistics (e.g., number of new cases reported) that can be shared within your agency to manage workflow Automatically sends summary reports in email or as email attachments to staff within		0	\bigcirc	0				
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Generates reports with summary statistics (e.g., number of new cases reported) that can be shared within your agency to manage workflow Automatically sends summary reports in email or as email attachments to staff within	Trend data based on syndrome, category, or jurisdiction		\circ					
Generates reports with summary statistics (e.g., number of new cases reported) that can be shared within your agency to manage workflow Automatically sends summary reports in email or as email attachments to staff within	Track patients who receive care outside of the jurisdiction	\bigcirc	\bigcirc	\bigcirc				
Generates reports with summary statistics (e.g., number of new cases reported) that can be shared within your agency to manage workflow Automatically sends summary reports in email or as email attachments to staff within	View or search for data based on custom parameters (e.g., chief complaint, diagnostic	osis)	\bigcirc	\bigcirc				
Generates reports with summary statistics (e.g., number of new cases reported) that can be shared within your agency to manage workflow Automatically sends summary reports in email or as email attachments to staff within	View or search for data based on custom patient characteristics (e.g., age group)	\bigcirc	\bigcirc	\bigcirc				
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Automatically sends summary reports in email or as email attachments to staff within		at can	\bigcirc	\bigcirc				
	Automatically sends summary reports in email or as email attachments to staff with	thin	\bigcirc	\bigcirc				
Integrated with the Health Alert Network (HAN) whereby alerts can be easily disseminated to other public health agencies and the medical community		\bigcirc	\bigcirc	\bigcirc				

	I do not use the feature	I use the feature some of the time	I use the fe most or all
Alerts when certain data categories are reported or a specific category exceeds "normal" levels	O	Some of the time	time
Export or extract data from this system to another system or application	\bigcirc	\cap	
Geographical Information System (GIS) views (e.g., ability to view lab reports by zip code or census tract)	Ŏ	\circ	Ö
Influenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring	\bigcirc	\bigcirc	
Patient demographics – ability to view patient contact information (e.g., phone no.)	Ŏ	Ŏ	$\tilde{\bigcirc}$
Patient-level health information (e.g., access to the patient's electronic medical records)	Ŏ	Ŏ	Ŏ
Patient-level vital signs (e.g., body temperature)			
Provider demographics – ability to view provider contact information (e.g., practice phone no.)	\bigcirc	\bigcirc	\bigcirc
Trend data based on syndrome, category, or jurisdiction	\bigcirc	\bigcirc	
Track patients who receive care outside of the jurisdiction	\bigcirc	\bigcirc	
View or search for data based on custom parameters (e.g., chief complaint, diagnosis)			
View or search for data based on custom patient characteristics (e.g., age group)		$\overline{\bigcirc}$	$\overline{\bigcirc}$
View or search for data based on custom time period (e.g., last month, from 1/1/2007 to 12/15/2008)	0	Ŏ	0
Generates reports with summary statistics (e.g., number of new cases reported) that can be shared within your agency to manage workflow	\bigcirc	\bigcirc	\bigcirc
Automatically sends summary reports in email or as email attachments to staff within the agency	\bigcirc	\bigcirc	\bigcirc
Integrated with the Health Alert Network (HAN) whereby alerts can be easily disseminated to other public health agencies and the medical community	\bigcirc	\bigcirc	\circ

Public Health Stakeholders

18. Syndromic Surveillance: System Perceptions

Please take a moment to think about the application or computer system you use most to interact with syndromic surveillance data. The following questions are in relation to this application or system.

30. Please indicate your level of agreement or disagreement with each of the following statements.

	Strongly	Moderatel Agree	Neither y Agree Nor	Moderatel		Not Applicable
			Disagree			_
The system improves the detection and management of emerging threats to public health		\circ	\bigcirc	\circ	\circ	\bigcirc
Data from hospitals are often missing, which requires me to look for it elsewhere (e.g., paper chart, phone, fax, email)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The system enhances our relationships with health care providers		\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The change in workflow required by the system has been problematic	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The format in which I receive HIE-provided data meets my needs			\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information is available when I need it	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
It is easy to use the system			\bigcirc		\bigcirc	\bigcirc
I rarely need to correct the data received from HIEs	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The data received is always accurate				0	0	
The format in which I receive hospital-provided data meets my needs						
The system enhances our ability to monitor the health of our community	0					
The data and information I use is rarely incorrect	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\circ
Data from the HIE are often missing, which requires me to look for it elsewhere (e.g., paper chart, phone, fax, email)	0		\bigcirc	\bigcirc	\bigcirc	\circ
The information provided by the HIE(s) is more timely than the information received directly from healthcare providers (e.g., hospitals)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I rarely need to correct the data received from hospitals	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information from the HIE is complete	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information received from hospitals is timely	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I receive the data when I need it	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The system makes my job easier	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I am satisfied with the quality of the data I am receiving	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I have needs that are not being met by the system	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
My work load has increased since I started using the system	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information provided by the HIE(s) is timely	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The data available to me help me make decisions	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Recent changes incorporated into the system enhanced its effectiveness	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The system improves the detection and management of notifiable conditions	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The data are easy to integrate into my other applications and reports	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The information from hospitals is complete	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc

Public Health Stakeholders	

statements.		Strongly Agree	Moderately Agree	Neither Agree Nor Disagree	Moderately Disagree	Stron
I am concerned that participation in an HIE will have a impact on public health practice	negative	\bigcirc	\bigcirc	\bigcirc	\bigcirc	
I am concerned that participation in an HIE will have a impact on patient privacy	negative	\bigcirc	\bigcirc	\bigcirc	\bigcirc	
I feel that participation in an HIE supports the public go		\bigcirc	\bigcirc	\bigcirc	\bigcirc	
I do not understand why public health needs to be invol projects	ved with HIE	\bigcirc	\bigcirc	\bigcirc	\bigcirc	
I would recommend participating in an HIE to colleague health departments	s in other	\bigcirc			\bigcirc	
32. In your opinion, what are the greinvolvement with an HIE? 33. In your opinion, what are the rehealth involvement with an HIE?	al or potenti	al chal	lenges o	r drawbad	ks to pu	blic
involvement with an HIE? 33. In your opinion, what are the re- health involvement with an HIE?	al or potenti	al chal	lenges o	r drawbad	ks to pu	blic
involvement with an HIE? 33. In your opinion, what are the replacement with an HIE? 34. Have you realized any unexpections.	al or potenti	al chal	lenges o	r drawbad	ks to pu	blic
involvement with an HIE? 33. In your opinion, what are the rechealth involvement with an HIE? 34. Have you realized any unexpectivith an HIE?	al or potenti	al chal	lenges o	r drawbad	ks to pu	blic
involvement with an HIE? 33. In your opinion, what are the rechealth involvement with an HIE? 34. Have you realized any unexpect with an HIE? Yes	al or potenti	al chal	lenges o	r drawbad	ks to pu	blic

Public Health Stakeholders
20. Final Questions
Please answer the following questions.
36. Approximately how much time (in minutes) did it take you to complete the survey?
37. Please provide your feedback on this survey. All comments, suggestions, and
complaints welcome.
38. May we contact you for follow-up?
Yes
○ No
39. Would you like to receive a report of findings from this survey?
Yes
○ No
40. If you would like a copy of the findings or you are interested in follow-up from the
survey, please provide your contact information.
Email Address:
Phone Number:

Appendix B

Survey of Infection Control Professionals

ICP Stakeholders

1. Welcome and Introduction

Dear Infection Control Professional,

A key function of public health agencies is surveillance or the ongoing, systematic collection, analysis, interpretation, and dissemination of data about health-related events. Recent public health events, such as the H1N1 outbreak, have renewed interest in and attention towards the improvement and sustainability of public health agencies' capacity for surveillance activities.

This survey was designed to capture IP/ICP knowledge and attitudes towards public health surveillance processes and hospital information systems involved in those processes. The survey asks a number of questions about the systems used in your facility(ies) that capture, analyze, and report surveillance data to public health. The survey also asks questions about health information exchange organizations that are expanding their capabilities to facilitate exchange of surveillance data between health care providers and public health agencies.

We thank you in advance for providing anonymous, honest answers regarding the infection control processes and information systems in use at your facility(ies).

This survey was developed and is being administered by a PhD student at Indiana University-Purdue University Indianapolis (IUPUI). All questions and concerns should be directed to Brian Dixon (bedixon@iupui.edu).

Please note that no record-level or identifying data will be released without prior consent. Aggregate findings will be included in the student's thesis, peer-reviewed publications, and presentations at conferences. Findings may also be shared with organizations such as the Centers for Disease Control and Prevention (CDC), the Association for Professionals in Infection Control and Epidemiology (APIC), and other professional organizations.

This survey has been approved by the IUPUI/Clarian Institutional Research Board (IRB), Study No. EX1010-24.

ICP Stakeholders
2. Information about You
Please begin the survey by providing some information about yourself and your role within the hospital or health network.
1. How would you characterize your role within the hospital or health network? (choose
ALL that apply)
I am responsible for managing the infection control program in my facility or network
I am responsible for monitoring disease incidence in my facility or network.
I am responsible for planning and/or implementing interventions to reduce infection and disease incidence in my facility or network
I am responsible for reporting disease incidence in my facility or network to public health entities.
Other (please specify)
2. Which of the following do you represent?
A network of hospitals or health care facilities
A single hospital or facility within a network
A single, independent hospital or health care facility
Other (please specify)
3. How long have you been at the hospital or health network?
Less than one year
1-2 years
2-3 years
3-5 years
5-10 years
10+ years

ICP Stakeholders
4. How would you describe your use of computers?
None – I prefer not to use computers, and when I do I find it difficult to get anything done.
Basic – I can use the computer to complete most tasks necessary for my job, but I rarely do anything with computers that I've not been shown how to do.
Average – I use the computer to complete tasks necessary for my job, and I occasionally play games, read news stories, pay bills, and/or purchase goods with the computer.
Advanced – I use the computer at work and home for many things, like reading news stories, playing games, and/or paying bills. I also consider myself handy with computers, doing things like installing new hardware (e.g., extra hard drive), configuring my home network, and burning CDs or DVDs.
Expert – I tend to not only use the computer for many things but also build, fix, and/or program computers at work and/or home.

ICP Stakeholders
3. Information about Your Facility or Network
Please provide information about your hospital/facility or health network.
* 5. What is the primary location of your hospital/facility or health network? City/Town: State: * 6. Does your facility participate in a Health Alert Network (HAN) with local and/or state
public health agencies?
Note: Answer Yes if at least one of the facilities in your health network is part of a HAN.
O No O Don't Know
For the next three questions, please enter a value between 0 and 10,000. If you do not know the answer to the question, please leave the answer space blank.
Note: If you are responding on behalf of a health network, please report numbers in the aggregate across facilities.
7. Total number of staffed beds (2009):
8. Hospital average daily census (2009):
9. Average number of ED visits per day:
10. Does your facility utilize an electronic health record (EHR) system?
Note: Answer Yes if at least one facility in the health network uses an EHR.
Yes
○ No
O Don't Know
11. Were you or someone else from infection control asked to participate in the design, selection, or implementation of the EHR system?
Yes
○ No
O Don't Know

ICP Stakeholders	

ICP Stakeholders
4. Relationship to Nearby Health Information Exchanges
Please provide information regarding your facility's relationship with any nearby health information exchange organizations.
* 12. How do you best characterize the relationship between your facility/network and regional/statewide health information exchange (HIE) organizations?
An HIE organization is defined as an organized entity, often a legal corporation, that specializes in facilitating electronic exchange of clinical and administrative health care data among a diverse group of often competing health care institutions, providers, and data repositories.
No HIE in my area
○ No relationship
Informal or dialogue only
Formally partnered by Memorandum of understanding (MOU) or other legal agreement
Non-voting (de facto) member
O Don't know
Other (please specify)

ICP Stakeholders
5. Current Data Exchange with Nearby HIE
* 13. Is your facility/network currently exchanging data with at least one HIE?
Yes
○ No
On't Know
14. Were you or someone else from infection control asked to participate in the
development or implementation of the data exchange with the HIE?
Yes
○ No
O Don't Know
15. Does the HIE have representation on its governance body (e.g., Board of Directors) from infection control/prevention?
Note: If the Board has representation by someone from another provider/facility, please answer Yes.
Yes
○ No
Oon't Know

ICP Stakeholders
6. Notifiable Conditions
The next series of questions pertain to notifiable conditions. If you are not familiar with how your facility/network handles the reporting of notifiable condition data (e.g., positive cases of syphilis), then you will be fast-forwarded to the next section of the survey.
Note: Notifiable Conditions for this survey are defined as those diseases (illnesses, conditions) that are either required to be reported by state law or voluntarily reported by states to the CDC for public health surveillance activities.
* 16. Are you familiar with how your facility/network reports notifiable condition data (e.g.,
positive cases of syphilis) to public health agencies in your region and/or state?
Yes
○ No

ICP Stakeholders
7. Current Notifiable Condition Data Reporting
The following questions pertain to the methods by which your facility/network reports notifiable condition data to public health agencies/jurisdictions in your region/state.
* 17. My facility/network reports positive cases of notifiable conditions (e.g., confirmed diagnosis for syphilis) to the following public health entities (choose all that apply):
Local Health Department
State Department of Health
U.S. Centers for Disease Control and Prevention (CDC)
Health Information Exchange
Don't Know
Other (please specify)
18. Reporting confirmed cases is typically done using a standardized Communicable Disease Report (CDR). What methods does your facility/network use for submitting the CDR to public health? Choose ALL that apply.
Print and Mail
Print and Fax
Electronic Fax
Secure Email
Non-secure Email
Manual Data Entry of Information using Web-based Reporting System provided by the Public Health Agency Automated Submission using the EHR System
Automated Submission using an Information System Other than the EHR
Electronic Submission using a Health Information Exchange
Don't Know

ICP Stakeholders	
19. Often it is necessary for a health care facility to submit documentation beyond the CDR (e.g., H&P's, lab reports, CXR's) when either initially sending the CDR or as part of a follow-up request from public health. How does your facility/network submit such documents? Choose ALL that apply.	
Print and Mail Print and Fax Electronic Fax Secure Email Non-secure Email Manual Data Entry of Information using Web-based Reporting System provided by the Public Health Agency Automated Submission using the EHR System Automated Submission using an Information System Other than the EHR Electronic Submission using a Health Information Exchange Don't Know	
20. What is the average time it takes you or your staff to review a notifiable condition case, including time to review the patient's chart, and prepare the case report for initial submission to public health? Less than 15 minutes Between 15 and 30 minutes Between 30 and 45 minutes	
Between 45 and 60 minutes More than 1 hour 21. How frequently are you or your staff contacted by public health regarding additional	
details related to a case report (e.g., request for the patient's telephone number, request for information from the patient's chart)? Almost never Rarely Sometimes Frequently	
Almost always	

ICP Stakeholders
8. Information Systems and Usage
Hospitals use a variety of computer-based systems to monitor infectious disease. This section will ask a variety of questions about the computer/information systems you use and your interactions with those systems.
* 22. Does your facility or network use a computer-based system or application to
review/access laboratory data, regardless of whether your organization or some other
entity (e.g., the state health department) developed it?
Yes
○ No
Opn't know

nformation Systems and Usage			
ase take a moment to think about the application or compute following questions are in relation to this application or systematics.		t to interact with l	aboratory da
23. What is the name of the computer system of laboratory-reported data?	or application tha	t you use to v	riew/acce
24 Who managed this system or application?			
24. Who manages this system or application?			
My hospital / facility (e.g., local IT staff)			
My network / ministry (e.g., central IT staff)			
Local health department			
State health department			
0.5			
Don't know			
Other (please specify)			
Other (please specify) 25. The following list contains features commo		_	-
Other (please specify) 25. The following list contains features common that allow access to laboratory-based data for extent to which they are available to you.	notifiable conditi	ons. Please ii	-
Other (please specify) 25. The following list contains features common that allow access to laboratory-based data for	notifiable conditi	ons. Please ii	Unsure whe
Other (please specify) 25. The following list contains features common that allow access to laboratory-based data for extent to which they are available to you.	notifiable conditi eature is not avai This feature available	ons. Please in	unsure whe
Other (please specify) 25. The following list contains features common that allow access to laboratory-based data for extent to which they are available to you. If a feature is unavailable to you, check "This follows when a lab result is positive for a notifiable condition (e.g., flags all	eature is not avai This feature available	ons. Please in	unsure whe
Other (please specify) 25. The following list contains features common that allow access to laboratory-based data for extent to which they are available to you. If a feature is unavailable to you, check "This follows when a lab result is positive for a notifiable condition (e.g., flags all chlamydia results)	eature is not avai This feature available positive	ons. Please in	unsure whe
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Other (please specify) 25. The following list contains features common that allow access to laboratory-based data for extent to which they are available to you. If a feature is unavailable to you, check "This followed is a lab result is positive for a notifiable condition (e.g., flags all chlamydia results) Alerts when a lab result is positive for a notifiable condition (e.g., flags all chlamydia results) Alerts when MRSA or other multi-drug resistant organisms are present/con Enables search for results pertaining to a given disease (e.g., find all chlaresults, find all MRSA cultures) Export or extract data from this system to another system or application Flags lab reports when there is a suspected case of infection	eature is not avai This feature available positive firmed mydia	ons. Please in	unsure whe
Other (please specify) 25. The following list contains features common that allow access to laboratory-based data for extent to which they are available to you. If a feature is unavailable to you, check "This followed a lab result is positive for a notifiable condition (e.g., flags all chlamydia results) Alerts when a lab result is positive for a notifiable condition (e.g., flags all chlamydia results) Alerts when MRSA or other multi-drug resistant organisms are present/con Enables search for results pertaining to a given disease (e.g., find all chla results, find all MRSA cultures) Export or extract data from this system to another system or application	eature is not avai This feature available positive firmed mydia	ons. Please in	unsure whe
Other (please specify) 25. The following list contains features common that allow access to laboratory-based data for extent to which they are available to you. If a feature is unavailable to you, check "This following is unavailable to you. Alerts when a lab result is positive for a notifiable condition (e.g., flags all chlamped is unavailable to you, check "This following i	eature is not avai This feature available positive firmed mydia ults by zip	ons. Please in	unsure whe
Other (please specify) 25. The following list contains features common that allow access to laboratory-based data for extent to which they are available to you. If a feature is unavailable to you, check "This for a notifiable condition (e.g., flags all chlamydia results) Alerts when a lab result is positive for a notifiable condition (e.g., flags all chlamydia results) Alerts when MRSA or other multi-drug resistant organisms are present/con Enables search for results pertaining to a given disease (e.g., find all chla results, find all MRSA cultures) Export or extract data from this system to another system or application Flags lab reports when there is a suspected case of infection Geographical Information System (GIS) views (e.g., ability to view lab resuccede or census tract)	eature is not avai This feature available positive firmed	ons. Please in	unsure whe

leature some of the time time time some of the time time time time time time time tim	a feature is unavailable to you, please skip to the n	I do not use the	I use the feature	I use the featur
Alerts when MRSA or other multi-drug resistant organisms are present/confirmed Canables search for results pertaining to a given disease (e.g., find all chlamydia esults, find all MRSA cultures) Export or extract data from this system to another system or application Canables search for results pertaining to a given disease (e.g., find all chlamydia esults, find all MRSA cultures) Export or extract data from this system to another system or application Canables search for results pertaining to a given disease (e.g., find all chlamydia esults, find all MRSA cultures) Canables search for results pertaining to a given disease (e.g., find all chlamydia esults, find all chlamydia esults		feature	some of the time	
Enables search for results pertaining to a given disease (e.g., find all chlamydia esults, find all MRSA cultures) Export or extract data from this system to another system or application Clags lab reports when there is a suspected case of infection Geographical Information System (GIS) views (e.g., ability to view lab results by zip code or census tract) Influenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring Patient demographics – ability to view the patient's contact information (e.g., phone co.) Patient-level health information (e.g., access to the patient's electronic medical		\bigcirc	\bigcirc	\bigcirc
esults, find all MRSA cultures) Export or extract data from this system to another system or application Clags lab reports when there is a suspected case of infection Geographical Information System (GIS) views (e.g., ability to view lab results by zip code or census tract) Influenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring Patient demographics – ability to view the patient's contact information (e.g., phone co.) Patient-level health information (e.g., access to the patient's electronic medical	lerts when MRSA or other multi-drug resistant organisms are present/confirmed	\bigcirc	\bigcirc	\bigcirc
Clags lab reports when there is a suspected case of infection Geographical Information System (GIS) views (e.g., ability to view lab results by zip code or census tract) Influenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring Patient demographics – ability to view the patient's contact information (e.g., phone color) Patient-level health information (e.g., access to the patient's electronic medical		Ŏ	Ŏ	Ŏ
Seographical Information System (GIS) views (e.g., ability to view lab results by zip code or census tract) Influenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring Catient demographics – ability to view the patient's contact information (e.g., phone lo.) Patient-level health information (e.g., access to the patient's electronic medical	export or extract data from this system to another system or application	\circ	\bigcirc	\bigcirc
code or census tract) Influenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring Patient demographics – ability to view the patient's contact information (e.g., phone onc.) Patient-level health information (e.g., access to the patient's electronic medical	lags lab reports when there is a suspected case of infection	Ŏ	Ŏ	Ŏ
Patient demographics – ability to view the patient's contact information (e.g., phone ob.) Patient-level health information (e.g., access to the patient's electronic medical		Ŏ	Ŏ	Ŏ
Patient-level health information (e.g., access to the patient's electronic medical	nfluenza-like Illness (ILI), Influenza, and Pneumonia tracking and monitoring		\bigcirc	
Patient-level health information (e.g., access to the patient's electronic medical		Ŏ	Õ	Ŏ
ecords)	atient-level health information (e.g., access to the patient's electronic medical	0	0	0

10. Syndromic Surveillance
The next series of questions pertain to syndromic surveillance. If you are not familiar with how your facility/network handles the reporting of syndromic data (e.g., chief complaints), then you will be fast-forwarded to the next section of the survey.
Note: Syndromic Data for this survey are defined as those data elements (e.g., chief complaint, number of school absentees) reported as initial manifestations of disease before clinical diagnosis has been confirmed.
* 27. Are you familiar with how your facility/network reports syndromic surveillance data
(e.g., ED registrations, chief complaints) to public health agencies in your region and/or state?
Yes No

ICP Stakeholders
11. Current Syndromic Surveillance Data Reporting
The following questions pertain to the methods by which your facility/network reports syndromic data to public health agencies/jurisdictions in your region/state.
* 28. My facility/network reports syndromic data (e.g., chief complaints) to the following
public health entities (choose all that apply):
State Department of Health
U.S. Centers for Disease Control and Prevention (CDC)
Don't Know
Other (please specify)
29. The primary method for reporting syndromic data to these entities is
Postal Mail
Fax
Web-based Reporting through a system provided by the Public Health Agency
Automated Electronic Reporting through the EHR
Automated Electronic Reporting through a Health Information Exchange
On't Know

statements.	Strongly Agree	Moderately Agree	Neither / Agree Nor		y Strongly Disagree	Not Applicat
Data from the HIE makes my job easier	\bigcirc	\bigcirc	Disagree	\bigcirc		\bigcirc
It is easy to use the HIE data or system	\sim	Ŏ	\sim	\sim	\sim	\sim
Communications from public health agencies about disease in my community is timely	Ŏ	Ŏ	Ŏ	Ŏ	Ŏ	Ö
Data and information I use is rarely incorrect	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The format in which I receive data meets my needs	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The data available to me help me make decisions quickly	\circ	\bigcirc	\bigcirc	\bigcirc		
Data provided by the HIE is always accurate	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	
The information in our computer systems is complete	0	O	O	0		
Data provided by the EHR is always accurate	0	0	O	0	0	0
The EHR system makes my job easier		\bigcirc	\bigcirc	\bigcirc	\bigcirc	
The EHR system enhances our ability to monitor the health of our patients	0		0	0		0
Data from the HIE make case reports more complete						
Data from the lab system rarely needs to be corrected before it is reported to publi health	ic O	0	0	0	\circ	0
I am satisfied with the quality of the data I receive from the EHR	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\circ	\circ
I am satisfied with the quality of the data I receive from the HIE	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	
Data from the HIE enhances our ability to monitor the health of our patients	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\circ	\circ
The information I need for my job is available when I need it	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	
It is easy to use the EHR system	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\circ
Data in the EHR are often missing, which requires me to look for it elsewhere (e.g paper chart, phone, fax, email)	., (0	0	0	0	0
I receive data when I need it	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I have needs that are not being met by the EHR system	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I have needs that are not being met by the HIE						

P Stakeholders				
. Open-Ended Questions				
	inion, what is one thing that public health agencies could do to bett in the reporting of notifiable condition and syndromic information?			
support ices	in the reporting of notinable condition and syndromic information?			
	▼			
	inion, what can EHR systems do to better support the work of infec	tion		
preventionists	s and infection control practitioners?			
	<u> </u>			

² Stakeholde				
. Final Questions				
ase answer the follow	ving questions.			
33. Approximat	ely how much time (in minutes) did it take you to complete the survey?			
	ride your feedback on this survey. All comments, suggestions, and			
complaints wel	come.			
35 May we con	utact you for follow-up?			
Yes	ract you for follow-up?			
○ No				
	like to receive a report of findings from this survey?			
Yes				
○ No				
	d like a copy of the findings or you are interested in follow-up from the			
Name:	provide your contact information.			
Email Address:				
Phone Number:				

Appendix C

Survey of Health Information Exchange Professionals

HIE Stakeholders

1. Welcome and Introduction

Dear HIE Professional,

Public health agencies protect the health and safety of populations. A key function of public health agencies is surveillance or the ongoing, systematic collection, analysis, interpretation, and dissemination of data about health-related events. Recent public health events, such as the H1N1 outbreak, have renewed interest in and attention towards the improvement and sustainability of public health agencies' capacity for surveillance activities.

This survey was designed to capture health information exchange (HIE) professionals' knowledge and attitudes towards existing information exchange activities that support public health surveillance. The survey asks a number of questions about your HIE, interfaces, and data that support surveillance (laboratory and syndromic) activities.

We thank you in advance for providing anonymous, honest answers.

This survey was developed and is being administered by a PhD student at Indiana University-Purdue University Indianapolis (IUPUI). All questions and concerns should be directed to Brian Dixon (bedixon@iupui.edu).

Please note that no record-level or identifying data will be released without prior consent. Aggregate findings will be included in the student's thesis, peer-reviewed publications, and presentations at conferences. Findings may also be

shared with organizations such as the Centers for Disease Control and Prevention (CDC) and professional organizations (e.g., AMIA, HIMSS). This survey has been approved by the IUPUI/Clarian Institutional Research Board (IRB), Study No. EX1010-24.

HIE Stakeholders
2. Information about You
Please begin the survey by providing some information about yourself and your role within the HIE.
How would you characterize your role within the health information exchange
organization?
Board Member
Development or Project Manager
☐ Epidemiologist
Executive Management (e.g., CEO, VP, Director)
Information Technology Professional (e.g., Engineer, Developer)
Other (please specify)
2. How long have you been at the organization?
Less than one year
1-2 years
2-3 years
3-5 years
5-10 years
10+ years
3. How would you describe your use of computers?
None – I prefer not to use computers, and when I do I find it difficult to get anything done.
Basic – I can use the computer to complete most tasks necessary for my job, but I rarely do anything with computers that I've not been shown how to do.
Average – I use the computer to complete tasks necessary for my job, and I occasionally play games, read news stories, pay bills, and/or purchase goods with the computer.
Advanced – I use the computer at work and home for many things, like reading news stories, playing games, and/or paying bills. I also consider myself handy with computers, doing things like installing new hardware (e.g., extra hard drive), configuring my home network, and burning CDs or DVDs.
Expert – I tend to not only use the computer for many things but also build, fix, and/or program computers at work and/or home.

HIE Stakeholders
3. Information about Your Organization
Please provide information about your HIE.
* 4. What is the principal location of your HIE?
State:
* 5. How would you characterize the HIE's level of development?
Initiating: Recognition of the need for health information exchange among multiple stakeholders in a state, region, or community. (E.g., public declaration by a coalition or political leader.)
Organizing: Getting organized; defining shared vision, goals, and objectives; identifying funding sources, setting up legal and governance structures. (Multiple, inclusive meetings to address needs and frameworks.)
Planning: Transferring vision, goals and objectives to tactics and business plan; defining needs and requirements; securing funding. (Not yet sharing data)
Implementing: Technical, financial and legal structures are being actively developed. (Pilot project or implementation with multi-year budget identified and tagged for a specific need.)
Operating: Operational health information organization; transmitting data that is being used by health care stakeholders. (Ongoing revenue stream and sustainable business model.)
6. What is the catchment area for your HIE?
Local (one to three cities/counties)
Regional within a state (several cities/counties)
Statewide (at least 80% of state's population covered)
Regional (across state boundaries)
Other (please specify)

HIE Stakeholders
4. Relationship to Nearby Local Public Health Jurisdictions
* 7. How do you characterize the relationship between the HIE and local health departments (e.g., city and county health departments)?
○ No relationship
Informal or dialogue only
At least one local health department fully participates through a Memorandum of understanding (MOU) or other legal agreement
All of them are formally partnered through a Memorandum of understanding (MOU) or other legal agreement
Other (please specify)

HIE Stakeholders						
5. Current Data Exchange with Nearby LHDs						
* 8. Are you currently exchanging data with at least one local health department?						
No Don't Know						
9. Does the HIE's Board or governance body have at least representative from a local health department?						
Yes						
O No O Don't Know						

HIE Stakeholders
6. Relationship to State Public Health Jurisdictions
* 10. How do you characterize the relationship between the HIE and the state health
department?
○ No relationship
Informal or dialogue only
The state health department fully participates through a Memorandum of understanding (MOU) or other legal agreement
The state health department is a non-voting (de facto) member
Other (please specify)

HIE Stakeholders						
7. Current Data Exchange with State Health Department						
* 11. Are you currently exchanging data with the state health department?						
○ No						
Onn't Know						
12. Does the HIE's Board or governance body have at least representative from the state health department?						
Yes						
○ No						
Don't Know						

HIE Stakeholders
8. Current Data Exchange Activities (Lab)
The following questions pertain to data categories of interest to public health agencies. You will be asked to provide details on the types of data the HIE currently exchanges or plans to exchange.
13. Does your HIE currently or plan to exchange laboratory-based data?
My HIE currently exchanges laboratory reports and/or result data
My HIE plans to exchange laboratory reports and/or result data
My HIE does not currently and does not plan to exchange laboratory reports and/or result data
I do not understand what this question is asking
None of these responses pertain to my HIE

system exists w exchange (e.g.,	=	_		-		
HIE).	·					
Hospital-based laboratory	Not Available and No	ot Used Availab	le but Not Used	Available and Us	ed [Don't Know
information systems (LIS) Independent Regional or	_					
National laboratory	\circ		\bigcirc	\bigcirc		\bigcirc
information management systems (LIMS) or LIS						
Public Health laboratory information management			\bigcirc			\bigcirc
systems (LIMS)						
access the data	or information	provided b	y a certain t	ype of syster	n.	
access the data	or information	provided by	y a certain t	e viewable by	n. v clinical p ntl Agency, such	
access the data For example, da but not public he	or information ta provided by ealth. Clinical Providers L	provided by	y a certain t	ype of syster	n. ⁄ clinical p	roviders
For example, da but not public he	or information ta provided by ealth. Clinical Providers L	provided by	y a certain t	e viewable by	n. v clinical p ntl Agency, such	roviders
For example, da but not public he Hospital-based laboratory information systems (LIS) Independent Regional or National laboratory	or information ta provided by ealth. Clinical Providers L	provided by	y a certain t	e viewable by	n. v clinical p ntl Agency, such	roviders
For example, da but not public he Hospital-based laboratory information systems (LIS) Independent Regional or	or information ta provided by ealth. Clinical Providers L	provided by	y a certain t	e viewable by	n. v clinical p ntl Agency, such	roviders
information systems (LIS) Independent Regional or National laboratory information management	or information ta provided by ealth. Clinical Providers L	provided by	y a certain t	e viewable by	n. v clinical p ntl Agency, such	roviders

HIE Stakeholders
16. If public health agencies (local or state) are allowed access to laboratory-based data,
how is the data provided to public health? (Choose ALL that apply)
Data are aggregated or summarized (e.g., GIPSE)
Data are de-identified
Data are transmitted in batch files at regular intervals (e.g., every three hours, once a day)
Data are queried by public health through a Web-based interface
Data are transformed from HL7 2.x (ORU) or HL7 v3 (HITSP C37) messages into a public health case report (in any format) and forwarded to public health
Data are provided to public health on an ad hoc basis and provided in highly customized formats
Don't Know
I don't understand what this question is asking
The responses to this question are confusing

HIE Stakeholders
10. Current Data Exchange Activities (Syndromic)
17. Does your HIE currently or plan to exchange syndromic surveillance data (e.g., chief complaints)?
My HIE currently exchanges syndromic surveillance data
My HIE plans to exchange syndromic surveillance data
My HIE does not currently and does not plan to exchange syndromic surveillance data

Current Data L	xchange A	ctivities (S	synaromic)			
18. The following		various sou	urce system	s that might l	be available	or send
syndromic data to	your HIE.					
Please indicate w	hether the id	entified sou	rce system	is available t	o your HIE (e.g.,
source system ex	ists within a	member or	ganization's	IT infrastruc	ture) and/or	used fo
data exchange (e.	g., source sy	stem is inte	erfaced and	sends or rec	eives data t	o/from t
HIE).	Not Available and N	lot Used Availah	le but Not Used	Available and Us	sed Do	on't Know
Emergency Department registration or ADT system		ot osed Availab	O	O	500	
Hospital-wide registration or ADT system	\bigcirc		\bigcirc	\bigcirc		\bigcirc
Physician practice registration or ADT system	\bigcirc		\bigcirc	\bigcirc		\bigcirc
Emergency Department financial/claims system	\bigcirc		\bigcirc	\bigcirc		\bigcirc
mianolal olamio oyotom				\bigcirc		\bigcirc
Hospital financial/claims	\bigcirc		\circ	$\overline{}$		
system Physician practice	0		0	\circ		\bigcirc
system Physician practice financial/claims system	0					
system Physician practice financial/claims system 19. Using the sam	=	-			_	
system Physician practice financial/claims system 19. Using the sam	=	-			_	
system Physician practice financial/claims system 19. Using the sam able to access the	e data or repo	orts availabl	e or sent fro	om a certain t	ype of syste	em.
system Physician practice financial/claims system 19. Using the sam able to access the For example, data	e data or repo	orts availabl registration	e or sent fro	om a certain t	ype of syste	em.
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HIE Stakeholders	
20. If public health agencies (local or state) are allowed access to syndron	nic
surveillance data, how is the data provided to public health? (Choose ALL	that apply)
Data are aggregated or summarized (e.g., GIPSE)	
Data are de-identified	
Data are transmitted in batch files at regular intervals (e.g., every three hours, once a day)	
Data are queried by public health through a Web-based interface	
Data are transformed from HL7 2.x (ORU) or HL7 v3 (HITSP C37) messages into a public health case report (in a forwarded to public health	ny format) and
Data are provided to public health on an ad hoc basis and provided in highly customized formats	
Don't Know	
I don't understand what this question is asking	
The responses to this question are confusing	

HIE Stakeholders 12. Perceptions 21. Please indicate your level of agreement or disagreement with each of the following statements. Neither Agree Nor Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree Disagree I am satisfied with current \bigcirc \bigcirc processes for syndromic data exchange I would like to see more \bigcirc \bigcirc \bigcirc \bigcirc laboratories participate in our HIE I am satisfied with current processes for laboratory data exchange Hospitals provide data to the HIE in a timely manner HIS and EHR vendors support available standards to the best of their ability Laboratory messages and data received from independent lab LIS is complete and requires little transformation Our Laboratory members support available standards to the best of their ability Data required to support our public health partners (local and/or state health departments) is available when they need it LIS and LIMS vendors support available standards to the best of their ability Laboratories provide data to the HIE in a timely manner Laboratory messages and data received from hospital information systems (HIS) and EHRs is complete and requires little transformation Laboratory message and data exceptions are handled in a timely manner by lab interface personnel Our Hospital members support available standards to the best of their ability Hospital message and data exceptions are handled in

HIE	E Stakeholders					
	a timely manner by					
	hospital interface personnel I would like to see more	\cap	\cap			
	public health departments participate in our HIE	O				
	22. How would you ra	-	-		s with data mes	ssaging
	standards (e.g., HL7) for laboratory data exchange?					
	Very Good					
	Good					
	Moderate					
	Poor					
	Very Poor					
	23. How would you ra	te compliar	nce by LIS and	LIMS vendors	s with data voc	abulary
	standards (e.g., LOIN	-	-			•
	Very Good					
	Good					
	Moderate					
	Poor					
	Very Poor					
	24. How would you ra	to compliar	see by HIS and	EUD vandars	with data mos	eaging
	standards (e.g., HL7)	-	=	LIII Vellaois	with data mes	saging
	Very Good		•			
	Good					
	Moderate					
	Poor					
	Very Poor					

HIE Stakeholders		
25. How would you rate compliance by HIS and EHR vendors with data vocabulary		
standards (e.g., LOINC, SNOMED) for data exchange?		
Very Good		
Good		
Moderate		
Poor		
Very Poor		
26. Does the HIE's Board or governance body have at least one representative from infection control/prevention?		
Yes		
○ No		
On't Know		

HIE Stakeholders				
	Open-Ended Questions			
27. In your opinion, what are the greatest real or potential benefits of public health involvement with a HIE?				
	28. In your opinion, what are the real or potential challenges or drawbacks to public health involvement with an HIE?			
	▲			
	29. Have you realized any unexpected outcomes from health department involvement with the HIE?			
	Yes			
	○ No			
ı	Please describe these unexpected outcomes.			

IE Stakeholders			
4. Final Questic	ons		
ease answer the following questions.			
30. Approximat	30. Approximately how much time (in minutes) did it take you to complete the survey?		
	31. Please provide your feedback on this survey. All comments, suggestions, and complaints welcome.		
32. May we con	ntact you for follow-up?		
Yes			
○ No	○ No		
33. Would you	33. Would you like to receive a report of findings from this survey?		
Yes			
○ No			
	34. If you would like a copy of the findings or you are interested in follow-up from the survey, please provide your contact information.		
Name:			
Email Address: Phone Number:			

Appendix D

Codebook

Purpose

This codebook provides a detailed description of the codes or themes used to classify the open-ended responses on the surveys provided to public health, infection control, and health information exchange professionals. The codebook was developed using a grounded theory approach, so it was edited and refined throughout the research study. This document represents the final version. The codebook contains the items as described as important by the Robert Wood Johnson Foundation's Common Analytical Approaches for qualitative research (http://www.qualres.org/HomeCodi-3828.html).

Codes

Code Word/Phrase	Description	Exemplars
Access	Viewing data or information on the screen; receiving data or information through any communication channel	"making [data] available to all hospitals" "Access to record level data from"
Accuracy	Data that represents the population, individual, or disease intended by the data entry clerk, clinician, or information system which input or transmitted the data	"making sure reports are accurate" "accurate data"
Completeness	Receiving the greatest number of reported cases for a given disease; receiving the greatest number of data attributes (e.g., patient phone number) possible	"greater capture of cases" "receive rich, timely healthcare data sets" "a more complete picture"
Decision Support	Utilizing available data, information, or knowledge to improve human decision-making processes	"decision making ability" "My system could help identify potential nosocomail infections" "Have some ability to "weed out" the ones that don't need to be looked at" "Utilize decision support

		software"
Ease of Use	Support for the end user's workflow. Ability to improve human efficiency. Feels "easy" to do by the	"data is easily accessed" "nothing to help the ICP pull data"
	end user.	"no one can run reports to pull the data"
Financial Resources	Cash, capital, credit, and other mechanisms to pay for systems or services.	"costs" "Cost is also always an issue in everything we do in public health." "money and time in era of budget cuts"
HIE	Direct mention of the phrase "health information exchange"	"HIE" "HIEs"
Human Resources	Staff, employees, human capital	"labor" "teach others how to use the system"
Integration	Access to information or data through a single interface, system, connection	"through one connection" "a central place"
Interoperability	Ability for disparate systems to exchange data and information	"How do we get the data from one system to the other?" "Communicate with other systems."
Outcomes	Individual patient or population improvement in health status	"better care" "better health outcomes for the population"
Paperless	Primarily electronic processes; reduction in the use of paper in surveillance processes	"Electronic submission of data" "I would love to be able to electronically send my reports to them." "Put reporting capability on-line."
Participation	Formal partnership with an HIE; exchanging data with an HIE	"Getting medical institutes to participate."
Portability	Ability to easily share information with others	"increase portability of info"

Privacy and Security	HIPAA, protected health information, confidential, secure data, data breech, misuse of information	"Breeches in data networks." "privacy issues, security of data issues" "how patient records are kept confidential and are only seen on a 'need to know' basis" "potential misuse of data by HIE's."
Redundancy	Repetition; multiple reporting streams with the same data but varying formats	"Not expect ICPs to report to multiple agencies in different formats." "less redundance from different agencies"
Regulation	Federal or state oversight of an entity	"who are the HIE's and who regulates their activities?"
Relationships	Formal or informal communication or exchange of data with a legally distinct organization	"may hurt relatioships with health care providers as state deals directly with providers"
Timeliness	Anything to do with time or the temporal dimension	"early detection of outbreaks" "time frame is much quicker" "Timely reporting of notifiable conditions" "Quicker follow-up"

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- Walker, J., Pan, E., Johnston, D., Adler-Milstein, J., Bates, D. W., & Middleton, B. (2005). The value of health care information exchange and interoperability. *Health Aff* (Millwood), Suppl Web Exclusives, W5-10-W15-18.
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Wurtz, R., & Cameron, B. J. (2005). Electronic laboratory reporting for the infectious diseases physician and clinical microbiologist. *Clin Infect Dis, 40*(11), 1638-1643.

Curriculum Vitae

Brian Edward Dixon

Education

Ph.D., School of Informatics, Indiana University, Indianapolis, IN, 2011

Concentration: Health Informatics Minor: Public Administration

Dissertation: The Perceived and Real Value of Health Information Exchange in Public

Health Surveillance

In this research, the value of HIE to the process of public health surveillance is explored. Specifically, the study describes the real and perceived timeliness, data quality, and usefulness of HIE in public health surveillance activities. To explore the real value of HIE, the study examined ELR data from two states, comparing raw, unedited data sent from hospitals and laboratories to data enhanced by an HIE. To explore the perceived value of HIE, the study examined public health, infection control, and HIE professionals' perceptions of public health surveillance data and information flows, comparing traditional flows to HIE-enabled ones. Together these methods, along with the existing literature, triangulate the value that HIE can provide public health surveillance activities as well as the remaining gaps that future research and development projects should explore.

M.P.A., School of Public and Environmental Affairs, Indiana University, Indianapolis, IN, 2005

Concentration: Public Management

B.A., DePauw University, Greencastle, IN, 2001

Major: Computer Science
Minor: Public Administration

Professional Experience

Regenstrief Institute, Inc., Indianapolis, IN, 2001 – Present

Health Information Project Manager (March 2005 – Present)

- Prepared and reviewed technical and cost proposals for extramural funding sponsors that detailed intended Statements of Work (SOWs), including scientific methods to evaluate the project's impact on health care quality, safety, efficiency, and effectiveness
- Directed, planned, implemented, monitored, and updated project schedules, deliverables, risks, budgets, and issues

- Communicated project status to principal investigators, upper management, and funding agencies, including progress and earned-value management (EVM) reports
- Designed data collection instruments, including surveys, interview protocols, databases, and Web-based applications
- Coordinated and monitored data collection and entry activities
- Performed analyses of literature relevant to research projects, data collected through research activities, and data extracted from biomedical databases
- Prepared technical and scientific reports and other deliverables for submission to internal teams and external stakeholders, including funding agencies
- Assisted in the preparation of manuscripts and abstracts for submission to scientific journals and meetings
- Facilitated project planning meetings and cross-team coordination
- Presented at scientific meetings and technical conferences

Computer Programmer (July 2001 – March 2005)

- Redesigned and supported the LOINC® Database and RELMA® Program, both are used by laboratories, hospitals and other health industry segments around the world to promote technology standards through the mapping of local institution codes to standardized LOINC® codes.
- Analyzed large datasets related to public health in the areas of cancer and communicable disease
- Designed and programmed in-house applications for use by health care researchers as well as clinicians

Teaching Experience

Health Information Exchange Data and Data Services: Types and Functionality INFO 582: Health Information Exchange School of Informatics Indiana University-Purdue University Indianapolis (IUPUI) February 7, 2010 Guest lecture for one class session.

A Roadmap for Funding Health Information Technology Projects Healthcare Information Management Systems Society (HIMSS) eLearning Academy

July 2009 – January 2010

The online course featured four modules: An Introduction to Health IT Funding and Strategies for Success, Identifying Funding Opportunities, Applying for Funding, and Managing Grants and Contracts. The course focused on teaching students how to prepare their organization to seek out, apply for, and manage external funding grants and contracts to offset costs associated with health IT implementation, adoption, and evaluation. Each course featured interactive elements to engage students along with an exam to test comprehension of the material. A final, comprehensive course assessment was also developed.

Grants, Contracts, and Research Projects

Active

Clinical Decision Support Consortium (CDSC), Option Year 1, Jul 2010 – Jul 2011 Agency for Healthcare Research and Quality (AHRQ)

Contract No. HHSA2902008100010

Demonstrate technologies developed for the CDSC in two primary care practice locations in Indianapolis, Indiana utilizing the Regenstrief CareWeb EHR application. Support the CDSC's ongoing work to develop and evaluate open knowledge management platform for decision support tools.

Role: Project Manager

Authorized Release of Medical Information through Integration with the Nationwide Health Information Network (NHIN), Mar 2010 – Present

Social Security Administration (SSA)

Contract No. SS00-10-60031

This project seeks to enhance the disability determination process through the exchange of electronic health record (EHR) data between providers and the Social Security Administration.

Role: Project Manager

Indiana Center of Excellence in Public Health Informatics, Sep 2009 – Present Centers for Disease Control and Prevention (CDC)

Grant No. 1P01HK000077

The project seeks to advance public health informatics through the development and maintenance of preeminent research, education, and practice. The project will support a number of multidisciplinary research and development activities in public health informatics over five years.

Roles: Project Manager and Researcher

Accelerating Public Health Situational Awareness through Health Information Exchanges, Oct 2008 – Present

Centers for Disease Control and Prevention (CDC)

Contract No. 200-2008-24368

This project involves the creation, use, and evaluation of novel informatics applications in public health for the detection and response to disease outbreaks within a health information exchange. Surveillance and bi-directional communication are key components of the project.

Roles: Project Manager and Researcher

National Health Information Network (NHIN) Trial Implementations, Oct 2007 – Present Office of the National Coordinator for Health Information Technology (ONC)

Contract No. HHSP23320074102EC

This project develops technology infrastructure for the Nationwide Health Information Network, a network of regional health information exchanges and large integrated delivery networks.

Roles: Project Manager, Standards Developer, Researcher

Closed

Care Transitions: Continuity Assessment Record and Evaluation Health Information Exchange Project, Sep 2009 – Nov 2010

Centers for Medicare and Medicaid Services (CMS)

Contract No. HHSM-500-2007-000181

This project seeks to develop and test novel methods for improving transitional care. The NHIN will serve as the platform for the project, with three health information exchanges to capture and exchange health information with CMS for the purpose of monitoring Medicare beneficiaries as they are transferred between care settings (e.g., inpatient, nursing home, ED, rehab).

Roles: Project Manager and Business Analyst

SHINE Project (Statewide HIV/AIDS Information Network), Oct 2008 – Mar 2010 National Library of Medicine (NLM)

Contract No. 00-608-6700

The SHINE Project creates and distributes Internet-based information resources to clinicians, public health professionals, and the general public regarding prevention, treatment, and management of HIV/AIDS.

Role: Web Architect / Designer, Usability Evaluator

National Resource Center for Health Information Technology, Sep 2004 – Sep 2009 Agency for Healthcare Research and Quality (AHRQ)

Contract No. 290-04-0016

This project supported the Agency and its Health IT Portfolio through technical assistance, portfolio management, research, and Web site development. Many aspects of the project involved the creation and dissemination of synthesis reports related to AHRQ-funded project findings, the adoption and use of health information technologies, and the impact of health IT on patient safety, quality, and effectiveness of care.

Roles: Project Manager, Researcher, Knowledge Manager

<u>Professional Appointments and Service</u>

Steering Committee, American Medical Informatics Association (AMIA) Invitational Policy Conference, 2010

- Planned the meeting schedule, topics, speakers, and logistics in collaboration with the other members of the committee
- Facilitated discussion in breakout groups
- Synthesized meeting notes and discussions
- Created meeting outputs, including peer-reviewed manuscripts and briefing materials for policymakers

Student Editorial Board, Journal of the American Medical Informatics Association (JAMIA), 2008 – 2010

- Reviewed 2-3 scientific manuscripts submitted to the journal each year while serving on the board
- Worked with assigned mentor to learn about the peer-review process and improve editorial skills

President, American Society for Public Administration (ASPA), Indiana Chapter, 2008 – Present

- Provided guidance and oversight on budgetary and programming activities
- Planned and managed 2-3 chapter events each year
- Worked with the National ASPA organization to cultivate an environment for the growth and development of public administration in Indiana
- Organized and facilitated meetings of chapter membership

Peer-Reviewer, Health Information Management Systems Society (HIMSS) Conference and Exhibition, 2008 – Present

- Reviewed 10-16 conference presentation proposals each year
- Worked with the public health and health information exchange review committees to establish the conference's programming

Peer-Reviewer, Journal of Health Information Management (JHIM), 2007 – Present

Reviewed 1-2 manuscripts each year

Peer-Reviewer, American Medical Informatics Association (AMIA) Symposium, 2007 – Present

- Reviewed 4-8 scientific abstracts and papers each year
- Worked with the scientific review committees to establish the conference's programming in the areas of health information exchange and public policy

Peer-Reviewer, Agency for Healthcare Research and Quality (AHRQ) Annual Conference 2007 – 2008

Reviewed 4-8 scientific abstracts each year

 Worked with the scientific review committee to establish the conference's programming in the areas of health information technology

Peer-Reviewer, International Health (Medical) Informatics Congress, Medinfo, 2007

- Reviewed 4-8 scientific abstracts and papers
- Worked with the scientific review committees to establish the conference's programming in the area of standards and interoperability

Civic Engagement and Service

Board of Directors, Hanover Homeowners Association, 2006 – 2008

- Presided over the Board as well as the Association's budget, contractors, and regulatory functions
- Worked with community residents to effectively monitor compliance with the Association's rules and regulations
- Organized and facilitated Association meetings

Board of Directors, College Mentors for Kids, Inc., 2003 – 2009

- Chaired the Information and Communications Technology (ICT) Committee
- Provided guidance and oversight on budgetary and programming activities
- Organized and assisted with program development activities

Program Coordinator, AmeriCorps, Bonner Leaders Program, 1999 – 2001

- Managed 7-12 AmeriCorps volunteers
- Organized and facilitated leadership development workshops
- Worked with community leaders to place volunteers in service roles

Professional Affiliations

American Medical Informatics Association (AMIA), 2006 – Present Health Information Management Systems Society (HIMSS), 2006 – Present American Society for Public Administration (ASPA), 2004 – Present

Peer-Reviewed Manuscripts

Dixon BE. Towards e-government 2.0: An assessment of where e-government is and where it is headed. Public Administration & Management. 2010; 15(2):418-454. Available: http://www.spaef.com/article.php?id=1256

Gamache R, Stevens KC, Merriwether R, **Dixon BE**, Grannis S. Development and assessment of a public health alert delivered through a community health information exchange. Online Journal of Public Health Informatics [Online]. 2010 Oct 26; 2(2). Available:

http://ojphi.org/htbin/cgiwrap/bin/ojs/index.php/ojphi/article/view/3214/2638

Zayas-Cabán T, **Dixon BE**. Considerations for the design of safe and effective consumer health IT applications in the home. Quality and Safety in Health Care. 2010 Oct; 19 Suppl 3:i61-7. doi:10.1136/qshc.2010.041897

Dixon BE, McGowan JJ. Enhancing a taxonomy for health information technology: an exploratory study of user input towards folksonomy. Studies in Health Technology and Informatics. 2010; 160:1055-9.

Dixon BE, Zafar A, Overhage JM. A framework for evaluating the costs, effort, and value of nationwide health information exchange. Journal of the American Medical Informatics Association. 2010 May-Jun; 17(3):295-301.

Dixon BE, Newlon C. How do future nursing educators perceive of informatics? Advancing the nursing informatics agenda through dialogue. Journal of Professional Nursing. 2010 Mar; 26(2): 82-9.

Dixon BE. Enhancing the informatics evaluation toolkit with remote usability testing. AMIA Annual Symposium. 2009: 147-151. PMCID: PMC2815364

Simonaitis L, **Dixon BE**, Belsito A, Miller T, Overhage JM. Building a production-ready infrastructure to enhance medication management: early lessons from the Nationwide Health Information Network. AMIA Annual Symposium. 2009: 609-613. PMCID: PMC2815381

Dixon BE, McGowan JJ, Cravens GD. Knowledge sharing using codification and collaboration technologies to improve health care: Lessons from the public sector. Knowledge Management Research & Practice. 2009 Aug; 7(3):249-259.

Dixon BE, Miller T, Overhage JM. Assessing HIE stakeholder readiness for consumer access: Lessons learned from the NHIN trial implementations. Journal of Healthcare Information Management. 2009 Summer; 23(3):20-5.

Whipple EC, McGowan JJ, **Dixon BE**, Zafar A. The selection of high impact health informatics literature: a comparison of results between the content expert and the expert searcher. Journal of the Medical Library Association. 2009 Jul; 97(3): 212-18. PMCID: PMC2706443

Zayas-Cabán T, **Dixon BE**. Consumer health IT design: Human factors considerations for devices and systems used in the home. Healthcare Systems Ergonomics and Patient Safety International Conference; 2008 Jun 25-27; Strasbourg, France.

Crandall DK, Brokel JM, Schwichtenberg T, Henderson S, Haskins R, Wakefield D, Ward M, **Dixon BE**. Redesigning care delivery through health IT implementation: Exploring

Trinity Health's IT model. Journal of Healthcare Information Management. 2007; 21(4): 41-8.

Dixon BE, Zafar A, McGowan JJ. Development of a taxonomy for health information technology. Studies in Health Technology and Informatics. 2007; 129(Pt 1): 616-620.

Zafar A, **Dixon BE**. Pulling back the covers: Technical lessons of a real-world health information exchange. Studies in Health Technology and Informatics. 2007; 129(Pt 1):488-92.

Dixon BE. A national roadmap for the adoption of e-health. E-Service Journal. 2007; 5(3): 3-13.

Dixon BE, Scamurra S. Is there such a thing as healthy competition? Proceedings of the 2007 Annual HIMSS Conference & Exhibition. 2007.

Peer-Reviewed Abstracts

Dixon BE, Grannis SJ. Enhancing public health reporting through health information exchange. HIMSS Conference and Exhibition. Orlando, FL; February 20-24, 2011.

Dixon BE, Trebatoski M, Grannis S, Dobbs DO. Geocoded Interoperable Population Summary Exchange (GIPSE): A data specification to enhance syndromic surveillance [Poster]. AMIA Annual Symposium. 2010.

Dixon BE. Using social networking sites when hiring informatics job candidates: A preliminary study [Poster]. MEDINFO 2010 - 13th World Congress on Medical Informatics. Cape Town, South Africa; September 12-15, 2010.

Dixon BE, Cusack CM, Zafar A, Whipple EC, McGowan JJ. Practical resources for health informatics professionals. MEDINFO 2010 - 13th World Congress on Medical Informatics. Cape Town, South Africa; September 12-15, 2010.

Dixon BE. Getting your health IT project funded: A practical guide. HIMSS Conference and Exhibition. Atlanta, GA; March 1-3, 2010.

Dixon BE, Xiao H, Grannis S. Reaching syndromic surveillance's last mile via health information exchange [Poster]. AMIA Annual Symposium. San Francisco, CA; November 14-18, 2009: 822.

Dixon BE, Zafar A. A web site for informatics implementation lessons and research outcomes. AMIA Annual Symposium. San Francisco, CA; November 14-18, 2009: 1132.

Dixon BE, Ho ATK, Kennedy SS. A roadmap to revitalize ASPA and its role in public administration. Southeastern Conference on Public Administration (SECoPA). Louisville, KY; September 30 – October 3, 2009.

Hills RA, Lober WB, **Dixon BE**, Grannis SJ, Lombardo J, Revere D. Demonstrating interoperability: Public health practice in a model health information exchange. PHIN Conference. Atlanta, GA; August 30 – September 3, 2009.

Grannis SJ, **Dixon BE**, Gibson J, Smiley A, Dearth S, Stevens K, Barnes M. Design and deployment of an integrated, standards-based public health alerting system. PHIN Conference. Atlanta, GA; August 30 – September 3, 2009.

Dixon BE. A practical guide to getting your health IT project funded. HIMSS Virtual Conference & Exposition; June 9-10, 2009.

Dixon BE, Zayas-Caban T. Five important usability challenges for informatics applications [Poster]. AMIA Spring Congress. Orlando, FL; May 28-30, 2009.

Dixon BE, Grannis SJ. Enhancing public health surveillance and communication through health information exchange. AMIA Spring Congress. Orlando, FL; May 28-30, 2009.

Dixon BE, Zayas-Caban T. Challenges in using telehealth to improve health care: lessons from the AHRQ Health IT Portfolio. AMIA Spring Congress; Orlando, FL; May 28-30, 2009.

Mohamoud S, **Dixon BE**, Zayas-Caban T. Developing interactive applications to enhance patient-clinician communication. AMIA Spring Congress. Orlando, FL; May 28-30, 2009.

Kaneshiro K, **Dixon BE**, Patton JD, Wilkinson M. SHINE project: Better health care through empowerment and information outreach [Poster]. HIV/STD Prevention in Rural Communities: Sharing Successful Strategies VI. Bloomington, IN; April 17, 2009.

Dixon BE, Cusack CM. Help is on the Web: AHRQ's National Resource Center for Health IT. HIMSS Conference & Exhibition. Chicago, IL; April 4-8, 2009.

Dixon BE. E-government 2.0: Early lessons. ASPA 2009 Annual Conference. Miami, FL; March 20-24, 2009.

Dixon BE, Zafar A, Whipple EC, Cravens GD, McGowan J. Facilitating informatics knowledge dissemination: targeted implementation resources for health care providers [Poster]. AMIA Annual Symposium. Washington, DC; November 8-12, 2008: 932.

Cravens GD, **Dixon BE**, Zafar A, McGowan J. A health information technology glossary for novices [Poster]. AMIA Annual Symposium. Washington, DC; November 8-12, 2008: 917.

Cusack CM, **Dixon BE**. Web-based tools from AHRQ's national resource center. AMIA Annual Symposium. Washington, DC; November 8-12, 2008.

Dixon BE, Dimitropoulos LL. Privacy and security solutions for health information exchange. HIMSS Conference & Exhibition. Orlando, FL; February 2008.

McGowan JJ, **Dixon BE**, McConnochie KM, Scheideman-Miller C, Bryant CA. Impacting quality and safety via telehealth. AMIA Annual Symposium. Chicago, IL; November 10-14, 2007.

Dixon BE, Samarth A, Starmer J. Improved management of chronic disease using health information technology [Poster]. AMIA Annual Symposium. Chicago, IL; November 10-14, 2007: 942.

Dixon BE, Samarth A, Starmer J. Lessons in using clinical decision support for chronic disease management. AMIA Spring Congress. Orlando, FL; May 22-24, 2007.

Dixon BE, Stamper MK, Cutshall A. Development of a registry to improve infection control efficiency [Poster]. AMIA Spring Congress. Orlando, FL; May 22-24, 2007.

Dixon BE. Using geographic information systems in public health [Poster]. AMIA Spring Congress. Orlando, FL; May 22-24, 2007.

Dixon BE. The landscape of the AHRQ health information technology portfolio [Poster]. AMIA Annual Symposium. Washington, DC; November 11-15, 2006: 912. PMCID: PMC1839591

Invited Presentations and Panels

Dixon BE. "Using Health Information Exchange to Improve Quality of Care." CMS QualityNet Conference. Baltimore, MD; November 30 – December 2, 2010.

Cusack CM, Poon EG, **Dixon BE**. "Evaluating Health IT Projects: A Practical Approach." MEDINFO 2010 - 13th World Congress on Medical Informatics. Cape Town, South Africa; September 12-15, 2010.

Dixon BE. "Bidirectional Communication: Enhancing Situational Awareness in Public Health and Clinical Practice." Interoperability Showcase – HIMSS Conference and Exhibition. Atlanta, GA; March 1-3, 2010.

Magruder C, **Dixon BE**. "Using the NHIN to Enhance Situational Awareness." National eHealth Collaborative Stakeholder Forum. Washington, DC; February 22, 2010.

Cusack CM, Poon EG, **Dixon BE**. "Evaluating Health IT Projects: A Practical Approach." AMIA Annual Symposium. San Francisco, CA; November 14-18, 2009.

Dixon BE. "Exploring Informatics with a Padawan: Using the Force to Improve Healthcare." Mathematics and Computing Colloquium Series. Franklin College. Franklin, IN; October 29, 2009.

Dixon BE. "Health Care IT Vendors Need to Hire More HCI Graduates and Other Things Health Care Needs to Do as It Reforms." Indiana Chapter of the Usability Professionals Association Meeting. Indianapolis, IN; October 14, 2009.

Price G, Somers D, Matthews M, **Dixon B**, Perez G, Gravely S. "NHIN Panel." HIMSS Conference & Exhibition. Chicago, IL; April 4-8, 2009.

Tokars J, Karras B, Dobbs D, **Dixon BE**, Stevens KC, Howell JF, et al. "Biosurveillance: Coordinating a Nationwide Approach." 5th Nationwide Health Information Network Forum: Trial Implementations - A Path to Production. Washington, DC: December 2008.

Dixon BE. "A Practical Guide to Securing Funds for Health Information Technology." Healthcare Financial Management Association Summer Conference, Show-Me of Missouri Chapter. Lake Ozark, MO; July 2008.

Dixon BE. "A Practical Guide to Grant Funding." Rural Health IT Conference. Kansas City, MO; September 2007.

Dixon BE. "The Role and Management of IT in the Public Sector." American Society for Public Administration (ASPA), Indiana Chapter Fall Meeting. Indianapolis, IN; October 2007.

Dixon BE. "Grant Funding for the Community Hospital: A Practical Guide." HealthLeaders Media Webinar; December 2006.

Dixon BE. "The Promise and Challenge of Transforming Health Care with Information Technology." DePauw University Information Technology Associates Program (ITAP) Lecture Series. Greencastle, IN; May 2006.

Dixon BE. "Health Communications Systems." Introduction to biomedical and health informatics [Tutorial]. AMIA Annual Symposium. Washington, DC; October 22-26, 2005.

Other Publications

Dixon BE. Health information exchange networks: A trend to watch. Global Forum. 2010. 2(6):29-31.

Grannis SJ, **Dixon BE**, Brand B. Leveraging immunization data in the e-health era: Exploring the value, tradeoffs, and future directions of immunization data exchange. Public Health Informatics Institute. 2010.

Dixon BE. Employer Perceptions and Use of Social Networking Tools When Hiring. Public Administration Times. 2010 Summer.

Dixon BE. Employer Perceptions of Social Networking Tools When Hiring Informaticists and Informaticians. AMIA Student Working Group Newsletter. 2010 Jul; 7(2): 5-7.

Dixon BE. Stimulating health care improvement through IT. Public Administration Times. 2009 Aug; 32(7): 6, 12.

Dixon BE, Zafar A. Inpatient Computerized Provider Order Entry: Findings from the AHRQ Health IT Portfolio (Prepared by the AHRQ National Resource Center for Health IT under Contract No. 290-04-0016). AHRQ Publication No. 09-0031-EF. Rockville, MD: Agency for Healthcare Research and Quality. January 2009.

Dixon BE, Samarth AS. Innovations in Using Health IT for Chronic Disease Management: Findings from the AHRQ Health IT Portfolio (Prepared by the AHRQ National Resource Center for Health IT under Contract No. 290-04-0016). AHRQ Publication No. 09-0029-EF. Rockville, MD: Agency for Healthcare Research and Quality. January 2009.

Dixon BE, Hook JM, McGowan JJ. Using Telehealth to Improve Quality and Safety: Findings from the AHRQ Portfolio (Prepared by the AHRQ National Resource Center for Health IT under Contract No. 290-04-0016). AHRQ Publication No. 09-0012-EF. Rockville, MD: Agency for Healthcare Research and Quality. December 2008.

Dixon B, Littlepage L. Indiana chapter hosts discussion on reform. Public Administration Times. 2008 Jul; 31(7): 15, 17.

Dixon BE. PA IT: Enhancing education, practice, and service. Public Administration Times. 2007 Dec; 30(12): 3.

Dixon BE, Wright DE, Quantz SA, Wright ER. Health information exchange: May cut costs and reduce medical errors, but raise challenges. Center for Urban Policy and the Environment; 07-C14. May 2007.

Dixon BE. IT security: Moving beyond technology toward policy and education. Public Administration Times. 2007 May; 30(5): 3-5.

Awards and Honors

Doctoral Consortium on Sociotechical Issues in Medical Informatics Participant, AMIA, IMIA, and NSF, 2010

Pi Alpha Alpha, Honor for Academic Achievement in Public Affairs and Administration, Indiana University Purdue University Indianapolis, 2005

Order of Omega, Honor for Outstanding Greek Leadership, DePauw University, 2001

National Education Debate Association Finalist, Transylvania University, 2000

Outstanding Individual Student Volunteer Award, DePauw University, 1999

Outstanding Achievement in Community Service Award, Interfraternity Council of DePauw University, 1999

Forensics Excellent Speakers Award, Delta Sigma Rho – Tau Kappa Alpha, 1999

Eagle Scout Award, Boy Scouts of America, 1994