Key Characteristics of Health Information Exchange: A Scoping Review

by

Yvonne Ng
BA, University of British Columbia, 1998

A Project Submitted in Partial Fulfillment
of the Requirements for the Degree of

Master of Science

in the Health Information Science

Supervisory Committee

Key Characteristics of Health Information Exchange: A Scoping Review

by

Yvonne Ng
BA, University of British Columbia, 1998

Supervisory Committee

Dr. Francis Lau, Department of Health Information Science
Supervisor

Jeff Barnett, Department of Health Information Science
Departmental Member

Abstract

Objective: To determine the size and nature of the evidence base for Health Information Exchange (HIE) and Regional Health Information Organizations (RHIOs) in the United States. Identify the key characteristics of successful RHIOs, barriers to HIE, and provide recommendations.

Methods: A scoping review of literature was conducted on HIE in the United States from 2006 through 2011. The reviewer abstracted HIE characteristics and organized findings into one of the five dimensions (Implementation, Technology, Policy, Data, and Value) of the Dixon framework.

Results: One hundred and sixteen peer-reviewed, non-peer-reviewed, and web publications were retrieved, and 11 met the inclusion criteria. Key characteristics of successful RHIOs include hybrid federated architecture, financial viability through recurring fees collected from participants, narrow exchange of test results, broad range of stakeholder types, and formal governance.

Conclusion: HIE progress has been slow in the last five years. Technical guidelines including architecture, data and messaging standards, as well as policy changes may improve RHIO progress. However, further evaluation of these changes is required to determine whether proposed guidelines are effective.

Table of Contents

Introduction

This is a scoping review to determine the size and nature of the evidence base for Health Information Exchange (HIE) and Regional Health Information Organizations (RHIOs) in the United States. Similar to a systematic review, it will be used to identify the extent, range of research and implementation issues with HIE. Once the current state of knowledge is synthesized and gaps in the current literature are identified, a list of successful HIE characteristics will be recommended for future implementations. Both HIE and RHIO will be examined in this paper.

While HIE development is in its nascent stages as implementation of HIE is still in formative stages,[1] it is important to identify characteristics for successful future implementations. Both RHIOs and HIEs are integral components of the United States government strategy to facilitate the development of a National Health Information Network (NHIN).[2]

A literature search was performed by one reviewer (YN) to identify studies involving HIEs and RHIOs within the last five years in the US. Studies were limited to peer reviewed literature describing successful HIEs. A successful HIE is defined as an operational HIE. Characteristics shared by operational HIEs will be extracted. An operational HIE is defined as those entities actively exchanging electronic data.[10, 11, 12,16]

The goal of the paper is to determine what would it take to for an HIE to be successful and then provide recommendations on how it can eventually advance to become part of an NHIN.

In 2006, there were over 300 RHIOs in the US consisting of multiple, competing enterprises that agreed to collaborate and build connectivity to move information among them, for the purpose of the patient.[3] Similar to a RHIO, an HIE is an entity that supports the electronic sharing of clinical data among dependent hospitals, physicians, and other health care stakeholders in a community.

Of the few studies that provide longitudinal data on RHIOs, one study found a quarter of RHIOs across the United States were likely to be defunct within twelve months.[4] RHIO progress proved to be slow as a survey of the U.S. RHIOs completed in 2007 reported only thirty-two operational RHIOs.[9] Furthermore, the scope of operational RHIOs were limited and focused on exchanging test results and inpatient data. The number of operational RHIOs nationwide increased to fifty-five in 2008,[10] and then reached a total of seventy-nine in 2009.[11]

The National Coordinator for Health Information Technology (ONC) was created by the previous Bush U.S. Administration to achieve interoperable health information technology in order to address fragmented personal health information.[6] The Health Information Technology for Economic and Clinical Health (HITECH) Act, part of the American Recovery and Reinvestment Act of 2009 stimulus bill provides incentive

payments for efforts to improve the health of Americans and the performance of their healthcare system.[7] Eligible providers must demonstrate improvement to the quality of healthcare through the electronic exchange of health information. NHIN has been proposed to link local and state HIE entities to create a nationwide health data exchange.[8] As a high rate of RHIO failure continues to persist,[9] it is essential to identify characteristics for successful RHIOs.

The objectives of this scoping review were as follows:

1. Identify studies on HIEs in the U.S.
2. Determine characteristics of successful HIEs
3. Identify HIE barriers and provide recommendations

Organization of the Report

This paper has been organized into seven chapters. The first chapter includes a history of HIE in the US. The next five chapters are dedicated to the method of the scoping review on the evidence base for operational HIE studies. In the remaining chapters, results categorized within the Dixon framework are reviewed. The final chapter summarizes findings of this research.

History

HIE efforts in the United States date back nearly two decades, with failures that far outnumber successes. In the early to mid 1990s, the Hartford Foundation initiated Community Health Management Information Systems (CHMIS) through grants to seven states and cities.[6] While CHMISs were primarily a community and payer-centric means to healthcare quality assessment, it was also a transaction system to facilitate billing and patient eligibility information retrieval. The architecture included a central data repository containing individual level demographic, clinical, and eligibility information for a geographically defined community.

Main challenges faced by CHMISs included a lack of affordable and effective technology.[6] In the early to mid 1990s, network connections, hardware, and software were to be costly items. For the first time, data sources that had never been combined required integration. Patients had security and privacy concerns with their data being stored in a single data repository. Correspondingly, providers had control and usage concerns. Obtaining consensus and cooperation between competing providers was difficult and at times unachievable. Since CHMISs were not financially self-sustaining, they were unable to transition past the grant funding stages.[6]

From the mid to late 1990s, community health information networks (CHIN) developed in communities interested in the concept of HIE. CHINs were focused on cost savings associated with moving data between providers.[20] In contrast to the quality assessment objectives of the CHMISs, CHINs had no commitment to make public community health level data.[21] Furthermore, a transaction-based approach to data allowed each provider their own database. Separate databases allowed CHINs to maintain independence and avoid relinquishing data to a central repository.[6]

Consequently, challenges that plagued CHINs arose as a result of the priority they placed on providers cost savings. With competitors assuming the role of community-focused stakeholders, the type and amount of information exchange was therefore limited.[6] Though this small group had a working knowledge of the problems and also had the ability to propose optimal solutions, success was dependent upon involvement across many disparate entities.[18]

With the potential for fees associated with electronic transmission, the role of technology vendor roles also increased. Though technical challenges were less of an issue than those faced by their predecessors, capital costs to build the infrastructure continued to be substantial.[6] In the end, CHINs were not able to demonstrate cost-effectiveness or meet expectations of consequential financial benefits.

Similar to CHMISs and CHINs, Regional Health Information Organizations (RHIOs) were created in geographically defined areas to facilitate health information exchange.

RHIOs developed in the 2000s with the objectives of quality and cost savings. According to the Healthcare Information and Management Systems Society (HIMSS), a RHIO is a 'neutral, third party organization that facilitates information exchange between providers within a geographical area to achieve effective and efficient healthcare'.

Contrary to CHMISs and CHINs, RHIOs developed during a period of significant political support. The Office of the National Coordinator for Health Information Technology identified RHIOs as the 'basic building blocks' of the American goal for a national health information infrastructure and interoperability.[22] Moreover, RHIOs also gained prominence from the influential Institute of Medicine Crossing the Quality Chasm reports.[23] These reports raised awareness about serious quality and safely shortcomings of the American Health System.[6]

With technology advancement in the 21st century, RHIOs have more cost effective options to building infrastructure and networking compared to their predecessors. It is important to determine whether RHIOs have overcome the challenges causing HIE efforts to fail in the 1990s. While HIE development is still in nascent stages, a review is necessary to determine progress and current state of HIE in the U.S. Future RHIO efforts may benefit from the identification of key characteristics of operational HIE implementations.

Review Methods

A literature search was performed by one reviewer (YN) to identify studies involving HIEs and RHIOs in the U.S. within the last five years to identify characteristics of operational HIEs. The project was carried out between May 2011 and March 2012.

Scoping Review

Whereas systematic reviews seek to synthesize evidence from different studies, scoping studies require an analytical framework or thematic construction to present a narrative account of existing literature. Furthermore, while systematic reviews assess quality of evidence for robustness or generalizability of findings, scoping studies provide an overview of all material reviewed and make no attempt of assessing the weight of an intervention.[5]

The complexity and rapidly changing nature of HIE and RHIO implementations [11] made it an appropriate subject for a scoping study. Since this area has not been comprehensively reviewed, a scoping review was used to map published literature into key concepts underpinning HIE. The purpose of this scoping study was to document and catalogue the extent of published material including gray literature (such as white papers) related to characteristics of operational HIE within the last five years. Five years was selected to account for the time it takes to become operational since RHIOs only commenced development in the 2000s.

Databases and Search Strategy

A search strategy was developed to retrieve all relevant studies on HIE and RHIO entities within the last five years. The literature searches included the following databases: CINAHL, Cochrane Database of Systematic Reviews, Medline, and PubMed. (See Appendix A for complete search queries.) In addition, relevant organizations and conferences such as Healthcare Information and Management Systems Society (HIMSS) and American Health Information Management Association (AHIMA) were searched for white papers on HIE and RHIO.

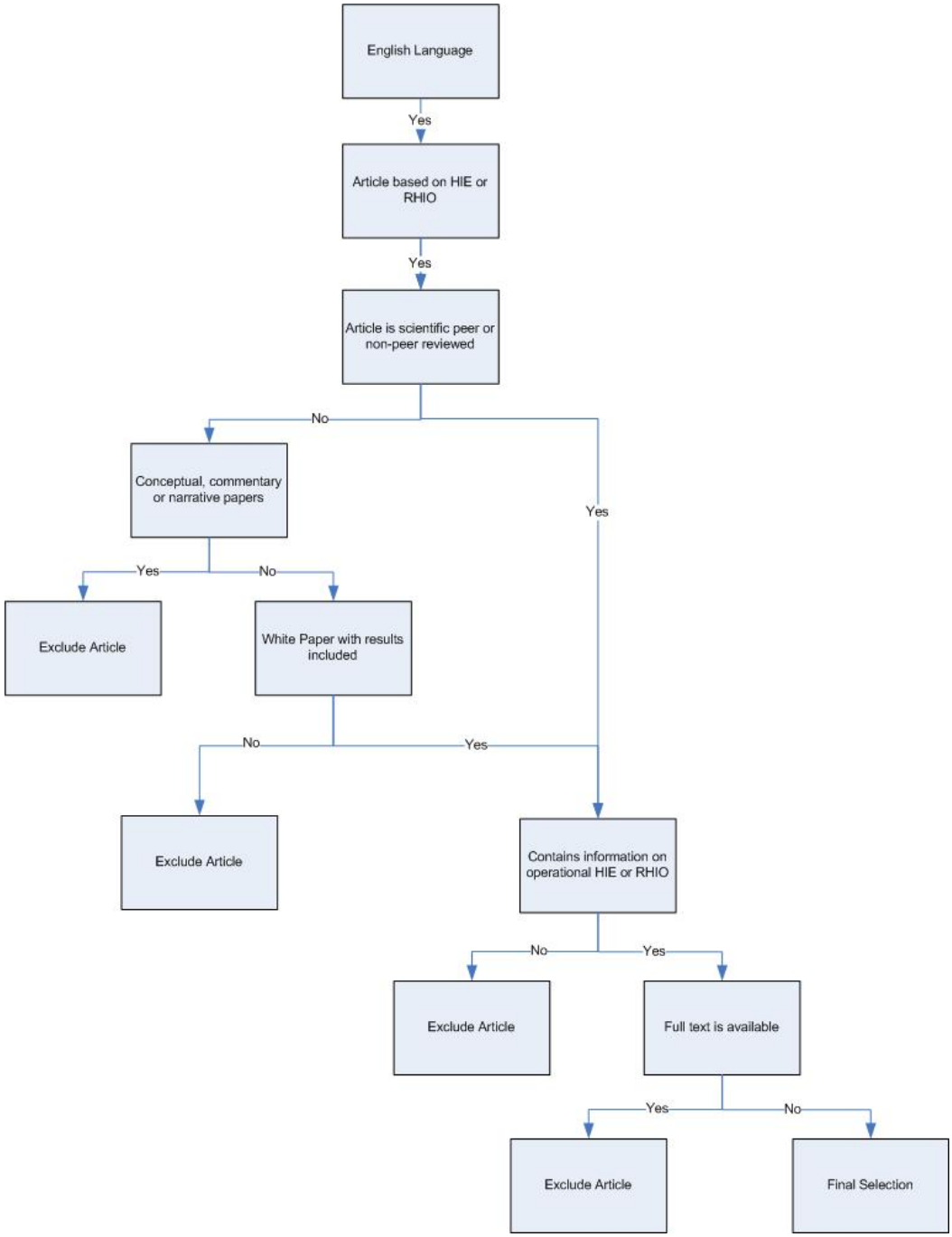
Searches were restricted to English language publications between January 2006 and December 2011. Additional cost and time for translation of foreign language material was not necessary since the focus is on the recent HIE efforts within the U.S.

Article Selection

To be included in the review, a full study report had to meet three inclusion criteria. First, the study had to involve either HIE or RHIO entities. Second, with the exception of whitepapers from relevant websites, only published scientific peer-reviewed and non-peer reviewed studies were considered. This includes observational studies, systematic reviews and evaluation survey studies. Conceptual papers, commentary papers, editorials, and narrative reviews on HIE and RHIO entities were excluded. Studies on HIE and

RHIO entities in planning stages were excluded unless they included data on operational stages as well. Figure 1 displays the inclusion and exclusion criteria used for article selection.

Figure 1. Article Inclusion and Exclusion Criteria



Data Extraction

One reviewer (YN) abstracted publications for findings related to predetermined characteristics of operational HIE and RHIO entities in the United States. Once a final set of studies including systematic reviews, evaluations, and white papers was determined, the general study characteristics, study objectives, HIE characteristics and issues were extracted from each study. Data were extracted into a table that summarized each study and a table on study goals.

Synthesis

A framework was required to organize key HIE concepts and issues as well as to make sense of the study findings. While evaluation reports in published studies are rare, general frameworks and methods for evaluating health information exchange are also scarce.[24] In determining a framework for this review, the Canada Health Infoway Benefits Evaluation Framework, Clinical Adoption Framework, Agency for Healthcare Research and Quality (AHRQ) HIE toolkit, as well as the Dixon framework were considered. Table 1 contains an overview of each framework assessed for appropriateness to this review.

Table 1. Framework Evaluation

Framework	Assessment for appropriateness
Benefits Evaluation Framework	Focus of framework is on Health Information System initiatives within an organization. Depth of information not captured in most HIE studies.
Clinical Adoption Framework	Meso and Macro view information available in most HIE articles, but Micro view information not provided in most studies
AHRQ HIE Toolkit	Provides general approach for developing an evaluation plan but does not include framework
Dixon Framework	Easily adaptable from nationwide data exchange to regional data exchange

Firstly, the Canada Health Infoway Benefits Evaluation (BE) framework was adapted from DeLone and McLean's Information System (IS) Success Model and developed for health information system (HIS) initiatives within an organization.[25] It includes conceptual dimensions for quality, use and net benefits of HIS adoption within healthcare organizations. As such, the BE framework was not applied since this level of detail was not captured in most of the HIE studies. Next, the Clinical Adoption Framework was considered for use in this review. While it was developed as an extension of the BE Framework,[26] the new set of meso- and macro- level factors provided more relevant dimensions. Whereas the meso view involved people, organizations, and implementation dimensions, the macro view involved healthcare standards, legislation, policy and governance.[26] Though both the meso and macro view are applicable to HIE, the depth of information required for the micro view (BE Framework) was not captured in most HIE studies. Thirdly, the AHRQ HIE Toolkit was also considered for this review due to the

nature of HIE. However, it was deemed inappropriate since it provides a general approach for developing an evaluation plan rather than an actual framework.

Lastly, the Dixon framework was considered for use to organize finding for this review. It was created for the purpose of evaluating costs, effort, and value of nationwide data exchange. Dixon et al reviewed various models and frameworks from a number of sources including peer-reviewed literature, the Markle Foundation, the eHealth Initiative, and the AHRQ National Resource Center for Health Information Technology. The previous models and frameworks were then synthesized and edited to reflect the nature of the interface specifications under development by the NHIN cooperative. With a mixture of qualitative and quantitative measures, the framework was developed to complement the NHIN technical, legal, and governance frameworks.[8] The framework further builds on traditional models used in local exchange efforts since regardless of the scope, data exchange involves similar function such as patient matching, privacy protections, and the need for standardized vocabularies.[8] As such, the Dixon framework was deemed most suitable for organizing the findings in this review.

HIE characteristics and issues were categorized in five broad dimensions of the Dixon framework (Table 2) and operationalized for this review as follows:

1. Implementation: This includes the number of operational HIEs in a study, HIE architecture, as well as data aggregation methods.

2. Technology: This includes HIE interoperability and data standards, as well as, how HIE barriers are encountered and overcome.
3. Policy: This includes stakeholder types, HIE governance, as well as consent in the form of provider/stakeholder/patient Opt-in or Opt-Out.
4. Data: This includes the scope and type of data exchanged in an HIE.
5. Value: This includes HIE funding and financial viability.

Table 2. Five Categories of the Dixon Framework

Category	Description
Implementation	Architecture compatibility with NHIN, operational costs incurred based on architectural choices, mechanisms for data aggregation, and core features implemented.
Technology	Technology choices and implications (i.e. open-source), standards harmonization achieved compared to NHIN recommended standards, costs incurred to attain harmonization, as well as how barriers are encountered and overcome.
Policy	Impact of NHIN policy on local HIE, stakeholder willingness to participate in local compared with national HIEs, how legal landscape at state-boundaries are addressed, and impact a change in administration on policy issues.
Data	Frequency of consumer access to data from other entities as well as metrics of data completeness such as the amount, comprehensiveness, and percentage of data available as a clinical result.
Value	Provider satisfaction and value, consumer satisfaction and value, cost and financial indicators, clinical outcomes, and sustainability model.

HIE characteristics from operational RHIOs and HIEs were extracted from each article and synthesized into each category. Most studies defined an operational HIE as an entity actively exchanging electronic data.[10, 11, 12,16] In determining whether an HIE or RHIO was successful, factors such as the length of time an entity was running and whether it is

operationally sustainable were not considered due to the lack of detailed information in most of the studies. For the purpose of this review, a successful RHIO is defined as an operational RHIO that is in active exchange of electronic data. An overview table containing qualitative or semi-qualitative finding information was included for each category.

Results

This section sets out the finding from the scoping review. An overview of the article selection process is provided, followed by two summary tables. The first table contains a summary of the study characteristics whereas the second table contains the study focus for each HIE article. Finally, the findings from the scoping review are then presented under each of the corresponding categories (Implementation, Technical, Policy, Data, and Value) of the Dixon framework.

The search yielded 1152 potential articles and 4 white papers for consideration. One reviewer (YN) performed an initial scan of all titles and/or abstracts, rejecting those that did not meet the criteria (n=1029). Figure 2 displays the selection process for articles from electronic databases and describes the inclusion criteria. The remaining articles (n=123) were then reviewed for selection based on titles, abstracts, and full text. Many articles were rejected during the initial scan because they were studies on specific health information technology such as personal health records, decision support systems, electronic health record, and electronic prescribing. Also rejected were descriptive

articles or articles without full text. Only 11 articles were identified that examined operational RHIO or HIE entities.[9-19]

The clinical settings for the 11 studies included hospitals, primary care practices, emergency medical service providers and other organizations involved with HIE. With the exception of one observational study and one systematic review, the remaining 8 studies were surveys. See Table 3 for study characteristics and Table 4 for a summary of the study focus for each HIE article.[9-19]

Figure 2. Article Selection Flow

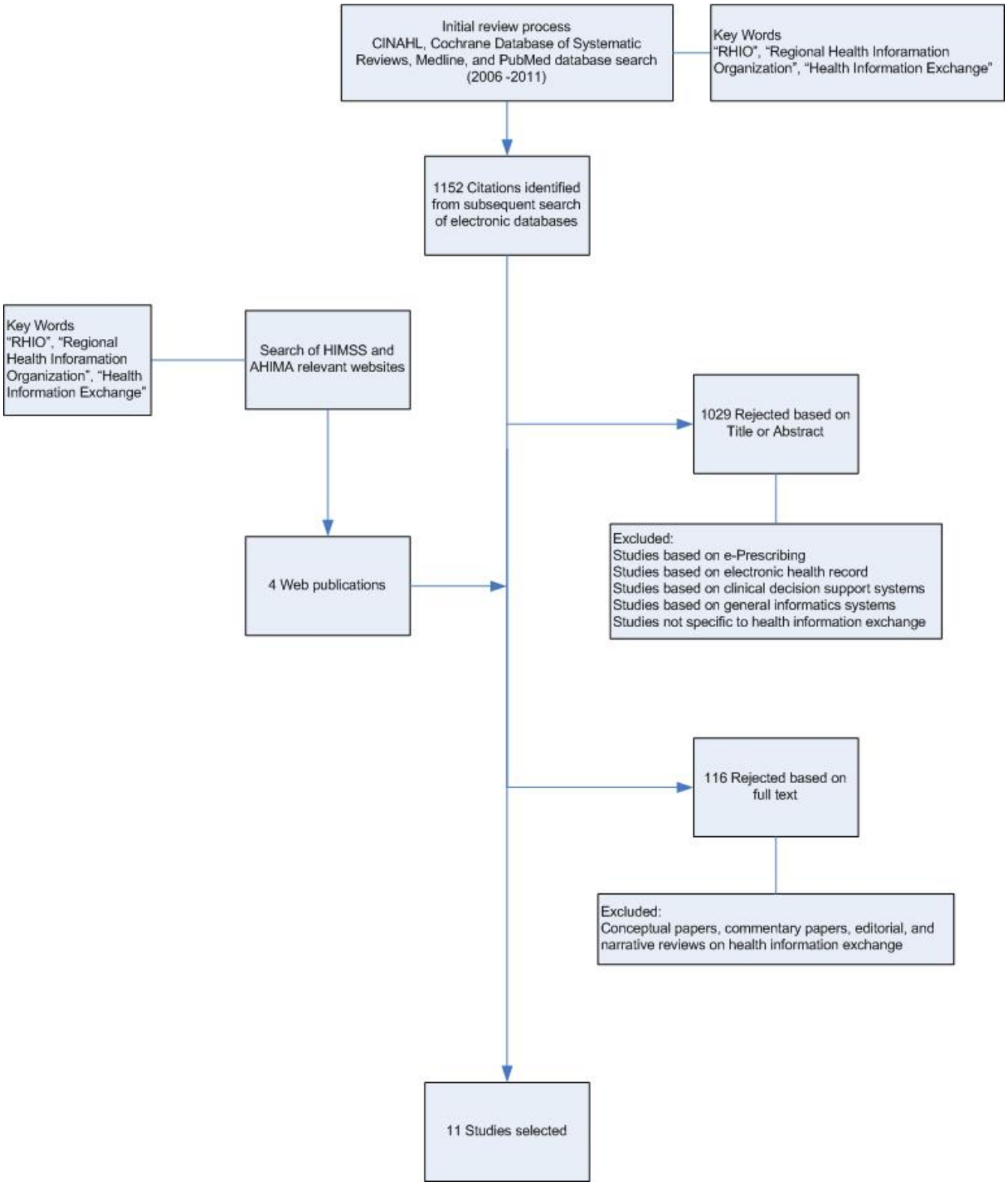


Table 3. General Study Characteristics

Reference	Design	Control Group?	Clinical Setting	Time Frame	Sample
Adler-Milstein (2009)[9]	Survey	No	Organizations involved in HIE	January 1, 2007 - June 1, 2008	N = 145 RHIOs as of June 1, 2008*
Adler-Milstein (2010)[10]	Survey	No	Organizations involved in HIE	Mid-2008	N = 207 RHIOs
Adler-Milstein (2011)[11]	Observational	No	Hospital: acute care	Spring - Summer 2009	N = 3725 Hospitals participating in regional efforts to electronically exchange clinical data
Adler-Milstein (2011)[12]	Survey	No	Organizations involved in HIE	December 2009 - March 2010	N = 247 Hospitals and ambulatory practices participating in operational RHIOs.
Finnell (2010)[13]	Survey	No	Emergency medical service providers	July 1, 2009; follow-up December 31, 2009	N = 180 EMS providers
Foldy (2007)[14]	Survey	No	Health care organizations	December 2006	N = 30 Healthcare organizations in Wisconsin
Fontaine (2010)[15]	Review	No	Primary Care Practices involved in HIE	January 1990 - mid-September 2008	N = 64 Publications on HIE in Primary Care Practices
HIMSS (2009)[16]	Survey	No	Organizations involved in HIE	2008	N = 21 Organizations actively

					exchanging data
Kern (2009)[17]	Survey	No	Community hospitals and physician practices, health plans, long term care facilities, home care agencies, local public health departments	January - February 2007; follow-up July - August 2008	N = 26 HEAL 1 grantees
McGowan (2007)[18]	Survey	No	Organizations involved in HIE	5 day period in July 2006	N = 5 Key leaders that were part of VITL since inception
Rudin (2009)[19]	Survey	No	Health care organizations	Summer and Fall 2007	N = 15 Executive officers from three communities with HIE capability

EMS = Emergency medical service; HEAL = Healthcare Efficiency and Affordability; VITL = Vermont Information Technology Leaders

* Contains data on Operational and Planned RHIOs

Table 4. HIE Study Goals

Reference	Main Focus	Goals
Adler-Milstein (2009)[9]	Analyze characteristics	Assess the state of HIE in the United States through RHIOs
Adler-Milstein (2010)[10]	Analyze characteristics	Identify factors associated with RHIO viability
Adler-Milstein (2011)[11]	Analyze characteristics	Identify key hospital-level and market-level factors associated with unaffiliated providers participating in HIE
Adler-Milstein (2011)[12]	Analyze characteristics	Assess the state of HIE in the United States through RHIOs
Finnell (2010)[13]	Evaluate impact	Assess impact of INPC HIE integration with EMS system
Foldy (2007)[14]	Analyze characteristics	Identify characteristics, challenges, and policy recommendations of HIE projects in Wisconsin
Fontaine (2010)[15]	Analyze characteristics	Analyze factors that motivate HIE participation in Primary Care Practices including benefits, barriers and overall value.
HIMSS (2009)[16]	Analyze characteristics	Assess common practices among operational HIEs in the United States
Kern (2009)[17]	Analyze characteristics	Assess state of HIE among HEAL 1 grantees
McGowan (2007)[18]	Analyze characteristics	Assess Implementation of Statewide HIE in rural Vermont
Rudin (2009)[19]	Analyze characteristics	Assess HIE development and viability in Massachusetts

EMS = Emergency medical service; HEAL = Healthcare Efficiency and Affordability; VITL = Vermont Information Technology Leaders

INPC = Indiana Network for Patient Care

Category 1: Implementation

The first category describes the architecture, data aggregation, as well as core features implemented in operational HIEs. This includes the cost and effort required to develop and instantiate various services called for in the Technology and Policy category, as well as mechanisms for data aggregation and core features implemented.[8]

Three studies reported majority of HIEs implemented a hybrid or federated architecture.[16, 18, 19] While a fully centralized approach involves a centralized data repository for all participants, the federated approach requires each participant to access data from the source participant through a network query. The hybrid approach combines aspects of a centralized and federated architecture through a central repository that is only a copy of a portion of the original data that is stored and maintained at the originating source. Each individual electronic health record submits the designated elements of new patient data to the centralized data repository where the data can be access by any site in the HIE network.[19] Under the hybrid approach, patient queries are performed only against the centralized repository instead of across all networks to each HIE participant site. See Table 5 for characteristics of HIE architecture.

The hybrid approach to data sharing uses both centralized and decentralized data sources in a federated model to satisfy an organization's desire for independence and ownership of data. Though participants maintain ownership over their patient's medical record, a copy (of some portion) is sent to a centralized repository that usually employs a centralized Master Patient Index and user registry.[16] Data is requested from the

centralized repository that contains a copy of a portion of the patient data instead of queried over the network.[19]

Table 5. Characteristics of HIE Architecture[19]

Feature	Fully Centralized (N=7)[a]	Federated (N=1)[b]	Hybrid (N=16)[c]
Centralized data repository	Yes	No	Yes
Network queries required	No	Yes	No
Ability to manage data	No	Yes	Yes

a = 7 participants in HIMSS (2009)[16] , b = 1 participant in HIMSS (2009[16]
c = 12 participants in HIMSS (2009)[16] + 1 participant in McGowan (2007)[18] + 3 participants in Rudin (2009)[19]

Data aggregation was included two studies.[13, 16] A 2009 Survey of operational HIEs reported that the provision of Master Patient Index (MPI) patient locator was among the initial services planned for HIE implementation.[16] Conversely, Indiana Network for Patient Care, a veteran HIE established in 1994, developed mechanisms for linking patients registered independently in different institutions and for linking physicians' master files. [13]

Category 2: Technology

The second category describes the technology characteristics of HIE implementation and operation. Interoperability issues and concerns were reported in five of the eleven studies.[9,14,15,16, 18] McGowan et al reported that immature national and international standards for data exchange made interoperability of information systems and sharing of data difficult and at times impossible for RHIOs in Vermont.[18] To address the challenge

of interoperability among hospital systems, the vendor selected must be able to provide a high-level scalable and sustainable system architecture that would handle HIE.[18] Likewise, several studies proposed structured programs or state and federal government assistance to mitigate technical challenges.[10, 12, 14, 15, 17] Fontaine et al reported while the lack of nationally recognized standards for data codes, storage, and retrieval; they also noted that the Health IT for Economic and Clinical Health (HITECH) Act within the 2009 American Recovery and Reinvestment Act (ARRA) established the Health IT Policy Committee and the Health IT Standards Committee.[15] Both of these committees are responsible for providing recommendations for policies, technical standards, and certification criteria for nationwide, interoperable health IT infrastructure. See Table 6 for a summary of HIE technical issues.

Table 6. Summary of HIE Technology Issues

Issue	Percent Reported in Number of Studies (N=11)
Interoperability	45%
Lack of structured programs or government assistance	45%
Lack of standards, implementation specifications, and certifications criteria	36%

Technical issues were reported in most of the studies. Four of the studies cited the need for technical issues to be addressed with the development of standards, implementation specifications, and certifications criteria.[9,10,15, 18] For example, the HIE Group recommended for certification of HIE components either through a third party or through

a set of agreements among the provider organizations.[10] Similarly, the State of New York also recognized the importance of standards and released a white paper on RHIO accreditation as a mechanism for defining standards to improve quality and ensure adherence.[17] A study by Foldy reported only a small portion of HIEs in the state of Wisconsin using standardized data vocabulary or transmission resulting in a lack of common data standards used in multiple systems sharing data. Consequently, the respondents recommended for statewide government or public-private partnership to establish standards for HIE, standardize geocoding of patient addresses across administrative databases, and also fund or mandate the use of Logical Observation Identifiers Names and Codes (LOINC) and Systematized Nomenclature of Medicine (SNOMED).[14] On the contrary, the Indiana Network for Patient Care (INPC) uses HL7 messages for nearly all interface flows and maps all data to standardized terminologies.[13]

Majority of HIEs supported Health Level 7 (HL7) as the common messaging standard, while International Classification of Diseases Revision (ICD-9), Current Procedural Terminology (CPT-4), LOINC-1, and National Drug Code (NDC) were reported as the common data standards.[16] Nonetheless, even with the development of interoperability standards and trial NHIN implementations there continues to be little progress on the breadth of data exchange and geographic coverage.[9, 10, 12, 17]

Category 3: Policy

The third category describes the governance characteristics of the operational HIEs and includes the privacy protections established.

While formal governance structures were identified as important in four of the studies,[12, 14, 17, 19] two studies furthered a broad group of participant types as stakeholders serving on an HIE board or Management Committee.[12,16] Kern et al reported that the New York eHealth Collaborative, a public-private partnership and statewide governance body, convenes Healthcare Efficiency and Affordability Law for New Yorkers (HEAL NY) grantees for statewide collaboration and development of policy guidance using a transparent governance process.[17] In an study by Foldy, recommendations for statewide government or public-private partnership action included the following: update state law to match Health Insurance Portability and Accountability Act (HIPAA), remove requirement for written permission from parents for collection of child health records, remove or address privacy barriers, and to create an understandable HIPAA standard for exchange.[14] Rudin et al furthered that an HIE's chances of success can be maximized through policies and programs that foster trust, appeal to strategic interests, and provide quality measurement benefits .[19] Finally, a 2009 survey of RHIOs in the US by Adler-Milstein et al reported operating as an independent organization with a formal governance structure and governing body as the key governance characteristics of operational RHIOs.[9]

Privacy and security concerns were also identified in seven of the studies.[9, 13, 14, 15, 16, 18, 19] In a 2006 survey of HIE in Wisconsin, participants recommended for statewide government or public-private partnership to remove or address privacy barriers.[14] Fontaine et al reported that patients and providers were concerned about privacy of protected health information in an electronic environment. They concluded that

governance, security policies, and establishment of rules for access and use of data were required.[15]

In contrast, the Indiana Network for Patient Care (INPC) HIE has an effective approach to addressing privacy and security issues. The INPC Management Committee is comprised of representatives from the HIE who serve as an additional level of oversight and also to establish policies for HIE.[13] They employ to a robust set of internal working policies for responding to a variety of governmental, stakeholder and consumer demands and concerns. Moreover, the INPC Management Committee also developed a comprehensive infrastructure, training, and policies and procedures to ensure security and privacy of a patient's protected health information. In addition to strict data-use agreements, strict security and authentication policies and procedures, INPC also employs a broad extent of the HIPAA security requirements.[13]

McGowan et al recommended public awareness as a strategy to mitigate privacy concerns, citing that education on the benefits of RHIO weighed against confidentiality issues should mitigate public concern.[18] A 2007 survey of HIE in Massachusetts found that having plans to employ clear policies and procedures for data access, including monitoring and sanctions resulted in an increase in provider trust.[19]

Finally, the 2009 HIMSS HIE Common Practices Survey concluded that information privacy and security is the cornerstone of any HIE organization [16]. Most participating

organizations cited all or a combination of the privacy and security strategies listed in Table 7 as either in use or planned for deployment.

Table 7. Summary of Policy Strategies [16]

	Description
HIPAA Compliance	Many reported conforming to HIPAA rules voluntarily, or due to business associate relationships with constituent partners.
Access Management	Function of both user authentication and authorization.
Role-Based Access	Uses definition of roles to determine who is requesting the data and can also be used as a proxy for access control.
Entity/Individual Authentication/Trust Model	Method of user authentication.
Auditing/Logs/Review	HIE entity activity logs for tracking of access and verification that data used for legitimate purposes. Logs most effective within entities that have a routine log review process to determine occurrence of any disclosure violations.
Health Information Security and Privacy Collaboration (HISPC)	The HISPC project is responsible for determination of appropriate privacy and security standards for HIE environments.

Category 4: Data

The fourth category describes the types and frequency of data exchanged in operational HIEs. This category includes data quality and the effort required to transform local data into standardized data mapped into normalized dictionaries, as this is essential for successful and sustainable HIE.[8] See Table 8 for a summary of HIE data types.

Table 8. Characteristics of HIE Data Types

Data Type	Adler-Milstein (2009)[9]	Adler-Milstein (2010)[10]	Adler-Milstein (2011)[11]	Adler-Milstein (2011)[12]	Finnell (2010)[13]	Fontaine (2010)[15]	HIMSS (2009)[16]	Kern (2009)[17]	McGowan (2007)[18]
Test Result	✔	✔	✔	✔	✔	✔	✔	✔	
Patient Demographics			✔	✔	✔				
Medication History	✔	✔	✔	✔				✔	✔
Public Health Reports		✔	✔	✔			✔		
Imaging Results			✔	✔			✔		
Inpatient Data	✔	✔	✔		✔		✔		
Discharge Summary			✔	✔					
Outpatient Data		✔					✔		
Summary Records			✔						
Clinical Notes						✔	✔		
Prescription							✔		

Majority of studies reported that operational RHIOs had a limited scope in clinical data exchange.[9, 10, 12, 14, 15, 16, 17] In a 2007 study, Foldy reported that little attention was paid to standardizing, indexing, and sharing of data for reuse resulting in much of HIE data in the state of Wisconsin to remain in separate, redundant silos.[14] In a 2007 study, Adler-Milstein et al reported that most RHIOs were focused on exchanging test results, inpatient data, and medication lists only. They attributed the narrow set of data types exchanged likely due to the tangible cost savings associated with electronic exchange as compared to traditional printing and mailing of results.[9] Adler-Milstein et al furthered that a pursuit of comprehensive data exchange may risk ability for self-sustainment and increase likelihood of failure.[9] Conversely, a 2008 study revealed that a narrow set of data exchange increased the likelihood of operational viability due to the simplified technical and potentially legal challenges faced by RHIOs.[10]

A subsequent study in 2009 by Adler-Milstein et al concluded that though RHIOs may receive start-up funding from public funds, there is a reliance on stakeholders for sustainability.[12] At that time, only 13 operational RHIOs in the US were capable of supporting the stage 1 meaningful use criteria set by Congress. Furthermore, none of the organizations supported the robust data exchange likely required to realize the projected quality and efficiency gains from HIE. Adler-Milstein concluded that RHIOs might be focusing on a narrow set of transactions with which they are able to deliver clear values to providers over a broader set of data exchange that may offer more intangible benefits.[12] Similarly, Fontaine et al argued that successful HIE implementations require

that a compelling vision be balanced with reasonable expectations and the ability to deliver a demonstrable benefit to providers. Therefore, an incremental approach that demonstrates early value without pushing stakeholders too fast is favored over an ambitious vision to build a community-wide, interoperable HIE from the ground up.[15] Kern et al reported that New York HIEs most commonly sought to exchange medication data and lab results, noting that data types did not change significantly over time.[17]

Category 5: Value

The fifth category describes the values characteristics of operational HIEs. This may include provider satisfaction and value; consumer satisfaction and value; cost and financial information as well as sustainability models. This category contains complex metrics associated with informatics evaluation such as patient outcomes, safety, return on investment, and any incremental value in the exchange of data beyond the local community.[8] See Table 9 for a summary of HIE Value Characteristics.

Table 9. Summary of HIE Value Characteristics

Value	Percent Reported in Number of Studies (N=11)
Cost Related Barriers Reported	63%
Grants and other funding key factors for RHIO start up and survival	36%
Robust business models and recurring fees important to RHIO financial sustainability	36%

Seven of the eleven studies reported that RHIOs faced cost related barriers.[9, 10, 14, 15, 16, 17, 18] A study by McGowan et al reported a lack of understanding about costs and value

proposition as an obstacle that participants felt could be addressed through extensive educational efforts.[18] Similarly, Fontaine et al argued that financial incentives could be used to address cost barriers.[15] In a 2007 study of US RHIOs, Adler-Milstein et al found that payers including insurers and employers rarely participate in data exchange or provide financial support.[9] Furthermore, the lack of rigorous evaluations to account for impact of operational RHIOs on the markets they serve means stakeholders are unlikely to provide support with HIE efforts. A 2008 study of operational RHIOs by Adler-Milstein et al concluded that RHIOs that received a grant as a moderate or substantial form of support in the planning phase decreased likelihood of financial viability as it may lead RHIOs to spend resources beyond ability to cover once grant funding ran out.[10] Financial viability was measured as the percent of operating costs and percent of capital costs covered by participants in data exchange or expected participants.

Grants and other beneficial funding were reported as key factors for RHIO startup and survival.[9, 10, 16, 17] This may include government grants and donations as funding sources or continuing financial contributions. Two studies found participant matching contributions from government grants as a characteristic for operational viability [10, 17] and reasoned that this signifies value of HIE by participants. Adler-Milstein et al argued that financial viability requires engaging a set of stakeholders who believe in the value of HIE and are also willing to pay for it. Furthermore, securing their financial support early is an important and distinct advantage.[10] Similarly, HIEs that received a one-time or recurring payment from participants while planning was identified as one of three independent predictors of greater financial viability in the 2009 HIMSS HIE Common Practices

Survey.[16] They also found that while many HIEs relied on grants and other beneficial funding in the long term, only some HIEs reported having the ability to survive through a sustainable business model that is not dependent upon grants.[16]

Several other studies recognized that robust business models and collection of recurring fees are important factors to RHIO financial sustainability.[9, 15, 16, 17] This may include time and in-kind resources, recurring subscription or transaction fees. Kern et al found that stakeholder buy-in was an essential financial barrier to sustainability.[1]

Discussion

Synthesis of Findings

To make sense of the findings, the Dixon framework was used to display characteristics of operational HIE entities from each study across the five categories (Table 10). For the purpose of this paper, a successful HIE entity is defined as an operational HIE that is actively exchanging electronic data. As the articles did not provide detailed information on each of the RHIOs included in each survey, it was not possible to determine how long each of the operational RHIOs had been actively exchanging electronic data. In addition, the studies included in this review did not include explicit information on successful RHIO/HIE but distinguished an operational RHIO against on that is planning for data exchange or defunct.[9, 10, 12, 3, 16]

Table 10. Characteristics of Operational HIE Entities.

Study	Implementation	Technology	Policy	Data	Value
Adler-Milstein (2009)[9]	32 operational RHIOs in 2007.	Development of interoperability standards and NHIN trial implementations signal federal commitment.	Grant funding as well as other policies spurred growth in number of RHIOs.	Focused on exchange of test results, inpatient data, and medication list.	Financial viability achieved through revenue from participating entities that cover operating costs.
Adler-Milstein (2010)[10]	55 operational RHIOs in 2008.	The HIE Work Group recommend certification of HIE components either through a set of agreements between the provider organizations or through a third party.	Broader group of stakeholder types increased likelihood of being operational as it allows the RHIO to leverage more resources.	Exchanged an average of 3 types of data.	Factors that increased HIE financial viability include: - spending less time planning for data exchange - ambulatory physicians and hospitals as data receivers - receipt of fees from participants during planning - judicious use of grants with participants matching contribution.

Table 10. Continued

Study	Implementation	Technology	Policy	Data	Value
Adler-Milstein (2011)[11]	1 in 9 US hospitals participating in HIE. Hospital level factors: - Non-profit - hospitals with larger market shares - Teaching hospital Market level factors: - Markets with lower Medicare spending - Concentrated markets		Policy response includes: - large grants to states - increasing EHR adoption - setting rules for data privacy, security and technical standards		
Adler-Milstein (2011)[12]	75 operational RHIOs in 2009.	ONC plans to achieve widespread HIE through grant funding and technical assistance to states expanding HIE and development of technical standards and NHIN to connect state and community entities.	- Stakeholders from broad group of participant types - Majority operated as an independent organization with a formal governance structure and body	Data types exchanged include test or imaging results, inpatient data, patient demographics, medication lists, discharge summaries, outpatient data.	Financial viability achieved through revenue from participating entities that cover operating costs.

Table 10. Continued

Study	Implementation	Technology	Policy	Data	Value
Finnell (2010)[13]	Independently registered patients from different institutions are linked.	All data are mapped to standardized terminologies and HL7 used for almost all interface flows.	- INPC Management Committee established a robust HIE policy to respond to governmental, stakeholder, and consumer concerns for confidentiality provisions - Employ strict security and authentication policies and procedures - Consent is provider/stakeholder/patient opt-out	Data types include demographics, laboratory data, ED and inpatient encounter data, coded diagnoses and coded procedures	Value of information important to deliver quality care especially when patients are unable to communicate their health history.
Foldy (2007)[14]	Operational exchanges include government organizations, health care professional organizations, academic institutions, and other nonprofit entities.	A small portion of HIEs used standardized vocabulary or data transmission while others exchange non-standardized data.	HIE initiated through legislative mandates, pre-existing funding, or association goals.		Reliance on government funding for operating revenue.

Table 10. Continued

Study	Implementation	Technology	Policy	Data	Value
Fontaine (2010)[15]	- Incremental implementation approach that demonstrates value without pushing the stakeholders too fast - Decentralized and Federated model the popular architecture	Technical barriers are being addressed with development of standards, implementation specifications, and certifications criteria for EHR.	Governance, security policies and establishment of rules for data access and use required to overcome privacy and security barriers.	Achievable early successes include test results and clinical notes.	- Cost barrier can be addressed with financial incentive - Long-term success of HIE initiative requires ability to provide services within a sustainable business model
HIMSS (2009)[16]	- Most HIEs had a hybrid or federated architecture - Majority used service oriented architecture (SOA) - Provision of Master Patient Index (MPI) patient locator services most cited as planned services by participants	Most HIEs support common messaging and data standards.	- HIE boards and management committees include stakeholders from broad group of participant types - most organizations deployed forms of privacy and security measure - Patient Consent Opt-In/Opt-Out	Lab results and prescriptions top functions.	- Government grants and other beneficial funding key to survival - HIEs with sustainable funding used membership model

Table 10. Continued

Study	Implementation	Technology	Policy	Data	Value
Kern (2009)[17]		Systematic solutions such as provision of technical support and updated applications to mitigate technical issues and workflow integration.	Formal governance structures extremely important. NY State released white paper on RHIO accreditation as mechanism for defining standards for quality and ensuring adherence.	Most commonly sought after data type includes medication and lab results which did not change significantly over time.	- Government provided grants where grantees matched the state funds in 1:1 ratio - Robust business models including cost/benefit sharing among stakeholders required to address financial sustainability.
McGowan (2007)[18]	Hybrid architecture	Collaboration between stakeholder groups to ensure interoperability among systems.	- Legislative bill authorized exchange activity - Public awareness to mitigate privacy concerns through education on RHIO benefits weighed against confidentiality issues to patients should mitigate public concerns	Medication history	State government provided seed money and funding.
Rudin (2009)[19]	Hybrid architecture		Plans in every community for clear policies and procedures on data access as well as monitoring and sanctions increased trust among participants.		State funding provided.

Here are recommendations based on the findings of this review. Each of the five categories (Implementation, Technology, Policy, Data, Value) lists the proposed chang that will guide RHIOs and HIEs with becoming successful in electronic data exchange In turn, successful regional HIE efforts may also lead toward a national HIE.

Proposed Implementation Characteristics

Under the Implementation category, a hybrid approach to HIE architecture is recommended. See Table 11 for proposed HIE architecture. While central data repositories were characteristic of CHMIS entities in the early to mid 1990s and a federated architecture was characteristic of CHINs in the mid to late 1990s, RHIOS ar increasingly adopting a hybrid approach to HIE architecture. [16, 18, 19] Since the hybrid approach is a combination of a centralized repository and federated approach, it allows participants to be custodians of their own data while also allowing for efficient sharing results through a centralized repository. See Table 11 for proposed HIE architecture.

Table 11. Proposed HIE Architecture

Architecture	HIMSS (2009)[16] (N=21)	McGowan (2007)[18] (N=1)	Rudin (2009)[19] (N=3)
Centralized Repository	33%		
Federated Approach	1%		
Hybrid Approach	60%	100%	100%

Other HIE system architectural elements should include a central registry of participating entities and users, as well as use of a record locator service. [16] Use of a Master Patient Index is the proposed method for data aggregation. [13, 16]

Proposed Technology Characteristics

At a high level, technology frameworks should include standards and procedures for systems to exchange information.[15] While interoperability issues were frequently reported,[9, 14, 15, 16, 18] a number of studies also cited the need for development of standards, implementation specifications, and certifications to address technical barriers.[9, 10, 15, 18] Though a majority of HIEs support HL7 as a common messaging standard and a variety of data standards,[16] there continues to be little progress on geographic expansion and breadth of data exchange. New RHIOs form and existing RHIOs expand as interoperability standards are being developed by NHIN. Statewide HIE initiatives will be faced with interoperability issues when connecting to local and regional HIEs that employ different levels of messaging and data standards.

A component of the technology framework should include a comprehensive set of data and messaging standards. Table 12 contains a list of proposed HIE data standards. Data standards should include ICD-9, ICD-10, CPT-4, LOINC-1, NDC, RxNorm, and SNOWMED. Data standards may be simplified with data and messaging standards. Use of standardized data may reduce the efforts for data normalization and transformation such as required when populating data in a portal.

Messaging standards should include Heath Level 7 (HL7), Digital Imaging and Communications (DICOM), National Council for Prescription Drug Program (NCPDP), and Accredited Standards Committee (ASC) X12. Table 13 includes a list of proposed messaging standards. Messaging standards such as HL7 coupled with Integrating the Healthcare Enterprise (IHE) implementation profiles are key strategies for exchange, integration, and sharing of electronic health information.[19] DICOM should be the

Table 12. Proposed HIE Data Standards

Standard	Foldy (2007)[14] (N=2)	HIMSS (2009)[16] (N=21)
ICD-9		86%
ICD-10		43%
CPT-4		81%
LOINC-1	100%	67%
NDC		53%
RxNorm		43%
SNOMED	100%	33%

Table 13. Proposed Messaging Standards [16]

Message	**Description**	**Foldy (2007)**[14] (N=2)	**HIMSS (2009)**[16] (N=21)
HL7	Health Level 7 transaction standards	100%	90%
DICOM	Digital Imaging and Communications standard for handling, storing, printing and transmitting of medical images		45%
NCPDP	National Council for Prescription Drug Program standards for communicating pharmacy claim information		50%
ASC X12	Accredited Standards Committee, an electronic data interchange standard for claims data		45%

standard set for handling, storing, printing and interchanging medical images. ASC X12 should be the standard set for electronic communication of claims data. In addition, messaging standards may also reduce the data translation efforts required to map data from one interface format to another.

Proposed Policy Characteristics

With regards to consent, HIE entities should allow patients to either "Opt-In" or "Opt-Out".[13, 16] Under an "Opt-In" model, patient data will not be included until specific approval is provided. Conversely, an "Opt-Out" model assumes that patient data will be included unless the patient specifically states otherwise.[16] In addition, these options can also be further refined to allow for opt in or out on the provider level, facility level, and data type.[16]

More importantly, policy makers should mandate the proposed HIE architecture (Table 11), proposed data standards (Table 12), and proposed messaging standards (Table 13). As suggested by some of the studies,[10,12,14,15,17] these structured programs can mitigate technical challenges. These components can be combined into one comprehensive HIE framework to be enforced by state or federal level government such as the ONC. Created for the purpose of achieving interoperable health information technology, it is also incumbent upon the ONC to implement policies to address privacy and security concerns for patients and providers. This level of governance may be able to complement any state or local privacy and security laws, while leaving states to implement stricter policies as desired. Other possible policies may also include certification for HIE vendors that offer

solutions that meet the specifications of the Technology Framework; financial incentive for existing HIEs to convert to new data and messaging standards for compliance; and funding opportunities for new HIE implementations that adhere to the Technology Framework.

Interoperability would likely improve with mandated data standards, causing the number of data types exchanged to increase. Frameworks that include the proposed HIE architecture and methods of data aggregation may decrease technical barriers faced by each HIE, resulting in improvements to HIE implementation. Instead of allocating significant time and resources on due diligence for technology options, data conversion, and interoperability, the value of each HIE may increase. In addition to improving local and community HIE implementations by decreasing the technological complexity, it may also minimize the efforts required to transform local HIEs for each connection and lay the appropriate foundation for nationwide data exchange. The cost of each implementation would likely decrease, as participants are no longer unique. Both financial and human resources that would have been previously been spent on investigation into technological solutions, requests for information, consultants, and trial-and-error implementation of new technology would no longer be necessary with the availability of a common HIE framework that includes architectural guidelines.

In theory, a comprehensive set of messaging and data standards would also require less effort for data transformation. More importantly, the data component would likely improve as the frequency and types of data exchanged by HIE entities increase. This will

increase the changes for achieving the broad scope of clinical data exchange called for by the current Obama administration.

Finally, entities should address privacy concerns as privacy and security concerns were reported in majority of the studies.[9,13,14,15,16,18,19] Instead of developing new policies, RHIOs and HIEs should start by reviewing existing privacy policies from mature and veteran HIEs that have demonstrated success in data exchange, operational and financial viability. The INPC would be an example of a successful HIE that possesses a robust set of internal working policies for responding to a variety of governmental, stakeholder and consumer demands and concerns.[13]

Proposed Data Characteristics

A number of studies found that operational HIEs exchanged a limited scope of clinical data types.[9,10,12,14,15,16,17] The narrow set of data types may be attributed to tangible cost savings[9] and simplified technical challenges[10] that are especially significant to RHIOs in their infancy. As such, entities planning to commence with electronic data exchange should focus on a limited set of data types to achieve early success. Table 14 contains a list of proposed HIE data types. This includes test results, patient demographics, medication history, public health reports, imaging results, inpatient data, discharge summary, clinical notes, and prescriptions.

Table 14. Proposed HIE Data Types	
Data Type	Reported in Studies (N=9)*
Test Result	90%
Patient Demographics	33%
Medication History	67%
Public Health Reports	44%
Imaging Results	33%
Inpatient Data	56%
Discharge Summary	22%
Outpatient Data	22%
Summary Records	11%
Clinical Notes	22%
Prescription	11%

* See Table 8 for list of each study reporting HIE data types

Proposed Value Characteristics

With most RHIOs reporting cost related barriers,[9, 10, 14, 15, 16, 17, 18] grants and other beneficial funding were reported as key factors for RHIO startup and survival.[9, 10, 16, 17] As such, it is important to have a robust business model that includes collection of recurring fees to ensure RHIO financial sustainability.[9, 15, 16, 17] Table 15 contains a list of proposed value characteristics. While RHIOs should take advantage of government funding and grants for start-up, it is essential that they also ensure revenue for long term sustainability.

Table 15. Proposed Value Characteristics

Value	Reported in Studies (N=11)*
Revenue in the form of fees from participants	46%
Government funding or grants for start-up	55%

In summary, key characteristics of HIE through operational RHIOs include a hybrid federated architecture, financial viability through recurring fees collected from participants, narrow exchange of test results, broad range of stakeholder types, and formal governance. Recommendations for RHIOs and organizations interested in electronic data exchange include: adoption of a comprehensive technical framework with a hybrid federated architecture, data standardization, and message standardization; comprehensive set of policies to address privacy and security concerns; as well as a list of proposed data types to commence clinical data exchange.

Limitations

There are some limitations in this literature review. The search was limited to English-language publications and duplicates were not removed from the total number of citations in the search of electronic databases. Though the value category of Dixon framework included a component on clinical outcomes, this was not included in the operationalized

value category and this data was also not available in the final study selection. As such, the findings in this study are focused on the resource component of the value category. However, a comprehensive reporting of value should include both a resource and clinical component.

The proposed Technical Framework is only a starting point based on literature from the study. There are a number of organizations such as HIMSS, AHRQ, AHIMA, IHE, eHealth Initiative, and RSNA that have created guidelines for various components of HIE. A comprehensive Technical Framework would be a separate project on its own requiring significant efforts for research and investigation into industry standards and existing efforts in place. In addition, the ONC has already released an interim final rule for an initial set of standards, implementation specifications, and certification criteria for EHRs in January 2010,[15] but a timeframe for the final deliverable is not yet known. In addition, a final Technical Framework should also include research into strategic implementation of terminology servers by the Department of Veteran Affairs (VA) and the Department of Defense (DoD). These terminology servers perform translation services from each agency's internal terminology to national standard terminology, allowing the VA and the DoD to achieve semantic interoperability in compliance with recommended national standards to perform real-time bi-directional data exchange [27].

Finally, due to the lack of detailed information contained in most articles, success was defined as an operational HIE actively exchanging data at the time of the study. However, due to the lack of longitudinal and detailed data, it was not possible to employ a stricter

definition of success to include factors such operational sustainability or financial viability. While operational sustainability would require data on the minimum number of years an HIE has been actively exchanging data, financial viability would require demonstration that HIE revenue exceeds operating costs to run HIE. Unfortunately, this data was not available.

Conclusion

A recent survey found many similarities in how HIEs are established, including start-up funding/entities, organizational structure and technical architecture. However, most HIE participants believed that they were unique, and therefore did not model their implementation after another HIE or follow any pre-established implementation guide in creating their HIE [16]. Hence, it may be valuable to the HIE community if a common set of guidelines were developed for organization structures, implementations, and technical architecture framework.

RHIO progress has been slow with a high rate of failures. Interoperability issues due to a lack of standards are significant contributing factors. Privacy concerns are imminent, requiring policies, agreements, and security strategies to mitigate [27]. RHIOs must also develop roust business models in order to achieve financial sustainability. The list of proposed implementation, technology, policy, data, and value characteristics for each of

the dimensions of the Dixon framework may provide a good starting point for successful electronic data exchange.

References

1. Edwards, A., Hollin, I., Barry, J., & Kachnowski, S. (2010). Barriers to cross--institutional health information exchange: A literature review. *Journal of Healthcare Information Management: JHIM*, *24*(3), 22-34.
2. Grossman, J., Kushner, K. L., & November, E. A. (2008). Creating sustainable local health information exchanges: Can barriers to stakeholder participation be overcome? *Center for Studying Health System Change NIHCM Foundation Research Brief No.*
3. Blair, R. (2006). RHIO nation. *Health Management Technology*, *27*(2).
4. Kern, L. M., & Kaushal, R. (2007). Health information technology and health information exchange in New York state: New initiatives in implementation and evaluation. *Journal of Biomedical Informatics*, *40*(6 Suppl), S17-20. Doi: 10.1016/j.jbi.2007.08.010
5. Arksey, H., & O'Malley, L. (2007). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32. Doi: 10.1080/1364557032000119616
6. Vest, J. R., & Gamm, L. D. (2010). Health information exchange: Persistent challenges and new strategies. *Journal of the American Medical Informatics Association: JAMIA*, *17*(3), 288-94. Doi: 10.1136/jamia.2010.003673
7. Blumenthal, D. (2010). Launching HITECH. *N Engl J Med*, *362*(5), 382-385. Doi: 10.1056/NEJMp0912825
8. Dixon, B. E., Zafar, A., & Overhage, J. M. (2010). A framework for evaluating the costs, effort, and value of nationwide health information exchange. *Journal of the American Medical Informatics Association: JAMIA*, *17*(3), 295-301. Doi: 10.1136/jamia.2009.000570
9. Adler-Milstein, J., Bates, D. W., & Jha, A. K. (2009). U.S. Regional health information organizations: Progress and challenges. *Health Affairs (Project Hope)*, *28*(2), 483-92. Doi: 10.1377/hlthaff.28.2.483
10. Adler-Milstein, J., Landefeld, J., & Jha, A. K. (2010). Characteristics associated with regional health information organization viability. *Journal of the American Medical Informatics Association: JAMIA*, *17*(1), 61-5. Doi: 10.1197/jamia. M3284
11. Adler-Milstein, J., DesRoches, C. M., & Jha, A. K. (2011). Health information exchange among US hospitals. *The American Journal of Managed Care*, *17*(11), 761-8.
12. Adler-Milstein, J., Bates, D. W., & Jha, A. K. (2011). A survey of health information exchange organizations in the United States: Implications for meaningful use. *Annals of Internal Medicine*, *154*(10), 666-71. Doi: 10.1059/0003-4819-154-10-201105170-00006
13. Finnell, J. T., & Overhage, J. M. (2010). Emergency medical services: The frontier in health information exchange. *AMIA ... Annual Symposium Proceedings / AMIA Symposium. AMIA Symposium*, *2010*, 222-6.

14. Foldy, S. (2007). Inventory of electronic health information exchange in Wisconsin, 2006. *WMJ: Official Publication of the State Medical Society of Wisconsin*, *106*(3), 120-5.
15. Fontaine, M. D., M. S., Ross, M. D., Zink, M. D., M. P. H., & Schilling, M. D., M. S. P. H. (n.d.). Systematic review of health information exchange in primary care practices. *Journal of the American Board of Family Medicine: JABFM [J Am Board Fam Med] 2010 Sep-Oct.*
16. HIMSS Health Information Exchange Best Practices Task Force. (n.d.). Health information exchanges: Similarities and differences. *Healthcare information and management systems society (HIMSS)*.
17. Kern, L. M., & Kaushal, R. (2007). Health information technology and health information exchange in New York state: New initiatives in implementation and evaluation. *Journal of Biomedical Informatics*, *40*(6 Suppl), S17-20. Doi: 10.1016/j.jbi.2007.08.010
18. McGowan, J. J., Jordan, C., Sims, T., & Overhage, J. M. (2007). Rural RHIOs: Common issues in the development of two state-wide health information networks. *AMIA ... Annual Symposium Proceedings / AMIA Symposium. AMIA Symposium*, 528-32.
19. RS, R. (2009). Understanding the decisions and values of stakeholders in health information exchanges: Experiences from Massachusetts. *American Journal of Public Health [Am J Public Health] 2009 May.*
20. Shortell, S. M., Bennett, C. L., & Byck, G. R. (1998). Assessing the impact of continuous quality improvement on clinical practice: What it will take to accelerate progress. *The Milbank Quarterly*, 593-624.
21. Starr, P. (1997). Smart technology, stunted policy: Developing health information networks. *Health Affairs*, *16*(3), 91. Doi: 10.1377/hlthaff.16.3
22. Solomon, M. R. (2007). Regional health information organizations: A vehicle for transforming health care delivery? *Journal of Medical Systems*, *31*(1), 35-47.
23. Squazzo. (2007). The state of regional health information organizations: Health data exchange on the rise. *Healthc Exec*, (22), 8.
24. Hripcsak, G., Kaushal, R., Johnson, K. B., Ash, J. S., Bates, D. W., Block, R., . . . Wilcox, A. B. (2007). The united hospital fund meeting on evaluating health information exchange. *Journal of Biomedical Informatics*, *40*(6 Suppl), S3-10. Doi: 10.1016/j.jbi.2007.08.002
25. Lau, F., Hagens, S., & Muttitt, S. (2007). A proposed benefits evaluation framework for health information systems in canada. *Healthcare Quarterly (Toronto, Ont.)*, *10*(1), 112-6, 118.
26. Lau, F., Price, M., & Keshavjee, K. (2011). From benefits evaluation to clinical adoption: Making sense of health information system success in canada. *Healthcare Quarterly (Toronto, Ont.)*, *14*(1), 39-45.
27. Bouhaddou, O., Warnekar, P., Parrish, F., Do, N., Mandel, J., Kilbourne, J., & Lincoln, M. J. (2008). Exchange of computable patient data between the department of veterans affairs (VA) and the department of defense (dod): Terminology mediation strategy. Journal of the American Medical Informatics Association : JAMIA, 15(2), 174-83. doi:10.1197/jamia.M2498

Appendix A: Literature Search Strategy and Search Terms

The following databases were searched for relevant studies: CINAHL with Full Text (EBSCO) (via UVic Lib 06/Jan/12); Cochrane Database of Systematic Reviews (via UVic Lib 06/Jan/12); Medline (via UVic Lib 06/Jan/12); PubMed (via UVic Lib 05/Jan/12).

The literature search used the following terms: "RHIO", "Regional Health Information Organization", and "Health Information Exchange". A manual search of relevant websites yielded additional web publications.

Inclusion/Exclusion Criteria

Intervention: Studies that assessed for operational HIE in the United States.

Participants: Health organizations, Ambulatory Clinics, Physician Offices

Outcomes: Inclusion criteria included: "success", "mature", "factors", "established", "challenge", "case study", "operational", "veteran" and "evaluate".

Study Designs: Scientific peer and non-peer reviewed papers.