

The Office of the National Coordinator for  
Health Information Technology



# Enabling Health Information Exchange to Support Community Goals

## *A Learning Guide*

*Presenting lessons learned by the 17 Beacon Community Awardees of the Office of the National Coordinator for Health Information Technology in the U.S. Department of Health and Human Services*

August 2013

The Beacon Community Cooperative Agreement Program demonstrates how health information technology (health IT) investments and Meaningful Use of electronic health records (EHR) advance the vision of patient-centered care, while supporting better health, better care at lower cost. The Department of Health and Human Services, Office of the National Coordinator for Health IT (ONC) is providing \$250 million over three years to 17 selected communities throughout the United States that have already made inroads in the development of secure, private, and accurate systems of EHR adoption and health information exchange. Each of the 17 communities—with its unique population and regional context—is actively pursuing the following areas of focus:

- Building and strengthening the health IT infrastructure and exchange capabilities within communities, positioning each community to pursue a new level of sustainable health care quality and efficiency over the coming years;
- Translating investments in health IT to measureable improvements in cost, quality, and population health; and
- Developing innovative approaches to performance measurement, technology, and care delivery to accelerate evidence generation for new approaches.

For more information about the Beacon Community Program visit <http://www.healthit.gov>.

This Learning Guide was developed by the Beacon Nation Project, funded by the Hawaii Island Beacon Community, an awardee of the ONC Beacon Community Program. The Beacon Nation project seeks to promote innovation in health IT by gathering and disseminating lessons learned from the 17 Beacon Communities about building and strengthening health IT infrastructure, testing innovative approaches, and making strides toward better care, better health, and lower costs.

For more information about the Beacon Nation project visit <http://www.beaconnation.org>.

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## Table of Contents

<b>Acknowledgments .....</b>	<b>i</b>
<b>Table of Exhibits .....</b>	<b>iv</b>
<b>Introduction .....</b>	<b>1</b>
Policies Driving HIE Adoption.....	2
The Current Data Exchange Landscape .....	4
<b>The Beacon Community Experience.....</b>	<b>6</b>
<b>Proven Strategies to Enable HIE in Achieving Community Health Goals.....</b>	<b>12</b>
Strategic Objective 1: Convene Stakeholders and Develop a Governance Structure to Foster Trust and Sustain Collaboration.....	12
Strategic Objective 2: Create a Legal Framework for Sharing Protected Health Information.....	31
Strategic Objective 3: Identify Funding Sources and Define the Financing Strategy.....	44
Potential HIE Services.....	47
Strategic Objective 4: Define Available Technology Paths to Facilitate Data Sharing.....	50
Strategic Objective 5: Define Measures, Monitor Progress, and Evaluate Success.....	60
<b>Looking Ahead .....</b>	<b>67</b>
<b>Appendices .....</b>	<b>1</b>
Appendix A: Summary of Key Decision Points Facing the Lead Convening Entity or Governing Board.....	1
Appendix B: State HIE Cooperative Agreement Program Exchange Models .....	3
Appendix C: Sample Data Use Agreement .....	4
Appendix D: Sample Evaluation Measures .....	7
Appendix E: List of Acronyms and Key Definitions .....	9
Appendix F: HIE Capability, Architecture, and Interoperability Standards— Resource List .....	12
Appendix G: Legal Framework—Resource List .....	14
Appendix H: References.....	15

## Table of Exhibits

Exhibit 1. Hospitals Electronic Exchange of Health Information with Other Providers, 2008-2012...	4
Exhibit 2. Overview of Selected Beacon Communities' HIE Strategies.....	6
Exhibit 3: Beacon Communities .....	11
Exhibit 4: Strategic Objectives .....	12
Exhibit 5: Stakeholder Group and Examples of Their Motivation to Exchange Data.....	16
Exhibit 6: Beacon Community Vision and Mission of HIE Initiatives.....	20
Exhibit 7: Southeast Minnesota Exchanges Data to Enable Public Health Case Managers to Work with Patients to Reduce the Risk of Readmission .....	22
Exhibit 8: Crescent City Beacon Community Exchanges Data to Enable Primary Care Providers to Be Notified of a Patient's Specialist Appointment, Appointment Occurrence, or No-Show and to Obtain Patient Summaries Following Specialists' Visits.....	23
Exhibit 9: The Governance Framework for Trusted Electronic HIE .....	25
Exhibit 10: Health Information Exchange Corporate Structures .....	26
Exhibit 11: Federal and State Legal and Regulatory Context.....	32
Exhibit 12: Key Attributes and Components of Data, Policies, and Trainings .....	34
Exhibit 13: Example Auditing and Logging Checklist from the Markle Foundation .....	42
Exhibit 14: Barriers to Health Information Exchange Identified by Planned and Operational Health Information Exchange Efforts .....	45
Exhibit 15: Elements of a Comprehensive Environment Scan .....	51
Exhibit 16: Prioritizing and Approving Community Evaluation Measures .....	61
Exhibit 17: Sample Operational Measures for HIE Capabilities.....	63
Exhibit 18: Sample Western New York Beacon Community Performance Measures.....	64
Exhibit 19: Common Gaps Identified by Measurement Activities .....	65
Exhibit A-1: Key Considerations in Achieving Strategic Objectives.....	1
Exhibit B-1: State HIE Awardee Exchange Mechanisms (Q1 2013) .....	3
Exhibit D-1: Proposed Southeast Minnesota Beacon Community Health Information Exchange Transition to Practice (HIETOP) Measures.....	7
Exhibit E-1: Acronyms.....	9
Exhibit E-2: Key Definitions.....	11

## Introduction

Electronic health information exchange (HIE) is a critical mechanism for improving the quality of care delivered to patients across the country. HIE is defined as the secure electronic movement of health-related information among health care entities according to nationally recognized standards.<sup>1</sup> Traditionally, patient health information has been difficult to share. It is done using manual and often time-consuming processes that require active coordination between the patient and provider teams and may involve the completion of numerous forms with mail and fax-based exchange of hard-copy health information. Electronic HIE allows patient health information to be shared across health care providers and institutions securely and efficiently, regardless of geographic or organizational boundaries. It allows information to follow patients across health care settings and visits. Prepared with timely, comprehensive, and up-to-date information on which to base care decisions, providers can improve both direct care delivery and the coordination of care across care settings.

HIE can be structured in a variety of ways and the structure is influenced by a number of factors, including, but not limited to: the goals and needs of the community, the mix of partners and available resources, and the financial strategies employed to sustain the HIE efforts. Efforts to establish exchange across the country are continuously evolving in the face of changing market dynamics and as new models for value-added HIE emerge. The Beacon Community Cooperative Agreement Program, funded by the Office of the National Coordinator for Health IT, includes 17 awardees that are demonstrating how health IT investments and the meaningful use of electronic health records (EHRs) advance the vision of patient-centered care, while achieving the three-part aim of better health, better care, and lower costs. While not the only goal of the Beacon Program, each Beacon Community is making investments in exchange capabilities to facilitate real care transformation and better health outcomes.

The Beacon Nation Project, launched by the Hawaii Island Beacon Community in early 2013, is translating the experiences and lessons learned from the Beacon Communities into actionable information that can be adapted for use by interested communities. This information is included in Learning Guides, which are a set of materials describing a promising IT-enabled intervention that can be deployed in a community to accelerate health care transformation.

The *Enabling Health Information Exchange to Support Community Goals* Learning Guide captures insights and guidance from the Beacon Communities around developing, enhancing, and strengthening HIE capabilities within a region to meet specified goals for improving health care and population health and increasing the efficiency of the health care delivery system. This Learning Guide also draws on information from other resources and provides key strategic objectives distilled from the Beacon Community experience and the literature to successfully implement HIE to support community goals.

.....  
[Learning Guides describe a promising IT-enabled intervention that can be deployed in a community to accelerate health care transformation.](#)  
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This Learning Guide is designed to help communities that are interested in establishing or enhancing existing HIE services to support their community health goals. Specifically this Guide provides practical information about the current landscape of exchange, available infrastructure and services, when regional collaboration offers value, and how to realize goals around exchange in a multi-stakeholder environment. Below are a few items to keep in mind while reviewing the materials:

- A Learning Guide is not an implementation manual with detailed checklists for installing a new system. Instead, the Learning Guide will lay out the most important decisions and considerations for a community interested in establishing or expanding its HIE services.
- The steps discussed in this document are laid out sequentially, but they often occur simultaneously. For example, a community can work to establish its governance structure and work to develop its legal framework for sharing information at the same time.
- Communities may have different levels of engagement and readiness when first referencing this Learning Guide. Organizing community stakeholders, identifying leadership, and facilitating collaboration and consensus on the vision and project goals require time.

**Target Audience:** This Learning Guide is designed for communities that are interested in establishing or enhancing existing health information exchange services in support of their community goals.

The remainder of this Learning Guide is organized as follows:

- The **Policies Driving HIE Adoption** section provides a broad overview of the HIE landscape – in particular the legal and policy drivers for HIE.
- The **Current Data Exchange Landscape** provides an overview of the commonly used HIE models and approaches.
- **The Beacon Community Experience** describes the Beacon Communities, their goals, and their strategies for establishing HIE services.
- Finally, **Proven Strategies to Enable HIE in Achieving Community Health Goals** builds upon the Beacon Community experiences and reflects five key strategic objectives needed to successfully implement HIE at the community level.

Physician practices adopting EHRs meeting the meaningful use criteria for a basic EHR system increased by more than 80 percent between 2009 and 2012 – from 22 percent in 2009 to 40 percent in 2012. Among acute care hospitals, this increase has been even more dramatic – an increase of 260 percent, from 12 percent in 2009 to 44 percent in 2011.<sup>ii</sup>

## Policies Driving HIE Adoption

Since the passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009, there has been tremendous growth in the adoption of health information technology (IT) and HIE. Through HITECH authority, the Office of the National Coordinator for Health IT (ONC) has played a critical role in accelerating improvements in HIE and

interoperability among electronic health records (EHR) systems, including the development of policies and standards to facilitate HIE, as well as through the funding of cooperative agreements and grant programs. Since Meaningful Use Stage 1 requirements were defined, physician adoption of the five core meaningful use functionalities – ranging from e-prescribing to clinical decision support – has grown by at least 66 percent.<sup>ii</sup> The Medicare and Medicaid EHR Incentive Programs, ONC’s Health IT Certification Program, the Standards and Interoperability Framework, the Direct Project, the Nationwide Health Information Network Exchange (NwHIN, which is now the eHealth Exchange), and the Integrating the Healthcare Enterprise (IHE) are all increasing standards-based HIE across health care providers and settings of care to support greater coordination of health care services.<sup>iii</sup> ONC also funds programs that more directly accelerate HIE improvements, including:

- The **State HIE Cooperative Agreement Program**, which addresses state efforts to build exchange capacity both within and across states.
- The **State HIE Challenge Grant Program**, which provides funding to State HIE Cooperative Agreement Program awardees to encourage breakthrough innovations for HIE that can be applied nationwide, including HIE use cases for long term and post-acute care.
- The **Beacon Community Cooperative Agreement Program**, which demonstrates how health IT investments and meaningful use of EHRs advance the vision of patient-centered care, while achieving the three-part aim of better health, better care, and lower costs.
- The **Exemplar Health Information Exchange Governance Entities Program**, a cooperative agreement program that funds entities to advance and further develop existing HIE governance models.<sup>iv</sup>

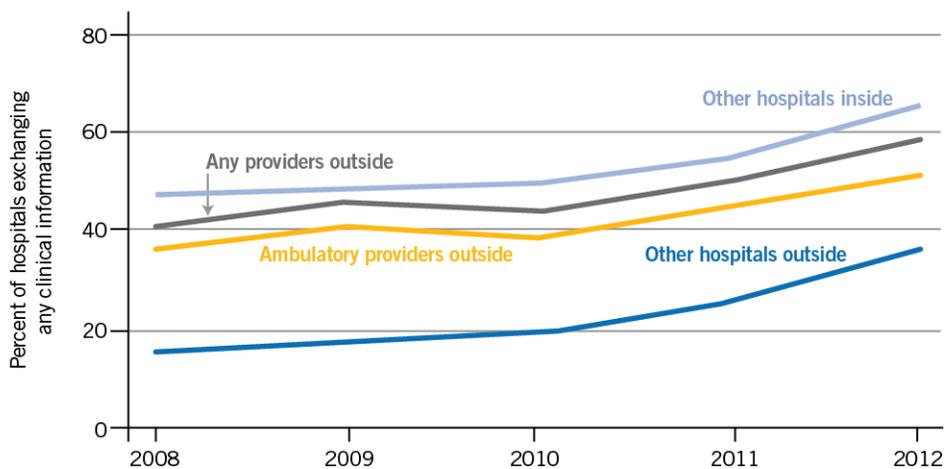
The passage of the Patient Protection and Affordable Care Act (ACA) in 2010 – combined with regulatory pressures, Federal incentives, and market demand – also set the stage for accelerating improvements to the nation’s health IT infrastructure and for improving the flow of information to support better health outcomes, population health management, and efficiencies in the U.S. health care system. The reorganization of delivery and payment systems for value-based accountability in health care service delivery is helping drive the demand for increased HIE to support care coordination and care management. Providers will be increasingly accountable

Accelerating HIE in support of delivery and payment reform will continue to be a joint, strategic priority for ONC and CMS. HHS has identified a set of principles to guide a comprehensive effort across HHS agencies to accelerate HIE, and to guide and inform HHS in making future decisions about health care programs and policies. They will also provide a framework against which to judge the formulation and implementation of programs and policies that build upon and move beyond the foundation of the EHR Incentive Programs and the ONC Health IT Certification Program. Where feasible, HHS plans to go beyond HITECH implementation and use appropriate authority to accelerate interoperability and electronic exchange of health information across the health care system.

for managing and coordinating the care provided to patients across multiple settings. For example, to reduce avoidable readmissions, a priority put forth in the ACA, providers will need to understand hospital admission, discharge, and transfer activities beyond their immediate system, and increase timely communication across different members of the care team. In this new environment, there is also greater need for health care quality measurement, other data analytics, and systems that can support such functionalities.

As a result of the improvements in technology, increased EHR adoption, and an improving business case, the portion of hospitals exchanging information both within and external to their organizations has substantially increased since 2008 (Exhibit 1).<sup>v</sup>

**Exhibit 1. Hospitals Electronic Exchange of Health Information with Other Providers, 2008-2012**



Source: Furukawa, M. F., V. Patel, D. Charles, M. Swain, & F. Mostashari (2013). Hospital electronic health information exchange grew substantially in 2008-12. *Health Affairs*. 8: 1346-1354.

### The Current Data Exchange Landscape

HIE goals may vary based on the needs of the community. Goals may include administrative efficiency, population health management, and improved health outcomes. For example, HIE capabilities have the potential to promote improvements in disease management, consumer engagement, medical error reduction, and health care quality. Specific goals might be to:

- Increase patient safety by enabling reception of current information on a patient’s medical status, medications, lab results, and allergies and contraindications to medication.
- Reduce duplicative treatments and tests.
- Create administrative efficiencies through decreased paperwork.
- Improve care management for specific subpopulations with chronic conditions and care coordination between the hospital and primary care practice environments.
- Track infectious diseases.

- Improve quality outcomes by facilitating patient-specific communication between care providers.
- Aggregate data to support more complete data analytics, research, and policy development.<sup>vi</sup>

In today's environment, three general models of exchange are emerging to support the goals described previously. Each represents a distinct objective and method for accessing data. These models are:<sup>vii</sup>

- **Directed Exchange:** Ability to send and receive secure information electronically between care providers to support coordinated care.
- **Query-Based Exchange:** Ability for providers to find or request information on a patient from other providers, often used for unplanned care.
- **Consumer-Mediated Exchange:** Ability for patients to aggregate and control the use of their health information among providers.

Appendix B displays the combined directed exchange and query-based exchange implementation status for all State HIE Cooperative Agreement Program awardees as of 2013.

While all of these models rely on a core set of standards and policies to transport, package, and structure information, they also require variable strategies to support the planning, governance, implementation, operations, and maintenance of each model of exchange.<sup>viii</sup> HIE models will vary in service offerings and supporting infrastructure – starting with some core functional services (such as patient directories) leading up to advanced functions, such as analytics tools. As service offerings and infrastructure become more complex, the level of governance and oversight required will increase. Similarly, the level of trust required among stakeholders and patients for more sensitive and complex data-sharing arrangements will also increase. For example, direct exchange models often enable exchange within a given health information service provider's (HISP) boundaries, while not offering mechanisms or supporting policies that enable exchange beyond those boundaries. Communities employing such models have begun using standardized data sharing agreements to enable providers using different HISPs to exchange direct messages. Once an agreement is executed, HISPs allow their respective users to seamlessly exchange messages. Such peer-to-peer legal agreements require a high level of oversight and monitoring to implement and enforce.<sup>ix</sup>

In addition, HIE models vary depending on the number and type of entities participating in data exchange. For example, sending and receiving information between a hospital and a lab does not require the same level of governance, oversight, and upfront consensus-building as a multi-provider query-based exchange with multiple service offerings. The timing of the implementation and local policies and regulations may also influence the model. Further, existing technology and participating members' adoption of electronic systems may play a significant role in determining the final exchange solution.

## The Beacon Community Experience

The Beacon Community Cooperative Agreement Program demonstrates how health IT investments and meaningful use of EHRs advance the vision of patient-centered care, while supporting better health and better care at lower cost. ONC provided \$250 million over three years to 17 selected communities throughout the United States that have already made inroads in the development of secure, private, and accurate systems of EHR adoption and health information exchange. Through these efforts, each community serves as a model of change that can help instruct the work of other cities, counties, and regions.

Each Beacon Community’s path to enhancing exchange and interoperability capabilities varied, depending on the community’s goals, drivers of improvement, and the existing systems and infrastructure in place at the beginning of the cooperative agreement program. When they received their awards, the Beacon Communities were at varying stages of maturity, which also influenced their ability to make progress against their HIE goals. The Keystone Beacon Community, Bangor Beacon Community, the Greater Cincinnati Beacon Collaboration, and the Central Indiana Beacon Community built on existing exchange efforts, for example, while others, such as Hawaii Beacon Community, established new services from the ground up. Exhibit 2 provides an overview of the range of starting points, exchange goals, and strategies utilized by the Beacon Communities that contributed to this Learning Guide.

*Exhibit 2. Overview of Selected Beacon Communities’ HIE Strategies*

Beacon Community	Overview
<b>Bangor Beacon Community</b>	HealthInfoNet is Maine’s statewide HIE and data repository. With the help of Beacon investments, the data repository now includes medical information on more than 1.1 million patients, representing 76 percent of Maine residents. HealthInfoNet provides authorized users with access to data regarding prescriptions, lab results, and medication allergies for 80 percent of the hospital stays in Maine. Established in 2006, it has experienced significant growth over the past three years and connects to 35 of Maine’s 38 hospitals and 385 ambulatory sites across the state. HealthInfoNet also supports access to clinical information for three home health organizations and two long term care facilities with additional connections planned in 2013. In total, HealthInfoNet ended 2012 with more than 6,500 authorized users of the exchange.



Beacon Community	Overview
<p><b>Central Indiana Beacon Community</b></p>	<p>The Central Indiana Beacon Community builds on the Indiana Health Information Exchange (IHIE), one of the oldest and largest health information exchange organizations in the country. IHIE connects more than 90 entities, including hospitals, long-term care facilities, rehabilitation centers, community health clinics, physicians, and other providers. IHIE provides consolidated, secure patient information such as lab results, medication and treatment histories, and other clinical data to more than 19,000 physicians in a standardized, electronic format. Through IHIE’s Quality Health First (QHF) program, physicians can identify patients with chronic disease, focus on early intervention and address any gaps in healthcare. Central Indiana is using its Beacon funding to incorporate richer, timelier data – including clinical data – into the QHF program and is expanding its reach from its nine original counties to 47 counties.</p>
<p><b>Colorado Beacon Consortium</b></p>	<p>The Colorado Beacon Consortium focuses on improving the health of its population through two major activities: implementing health IT upgrades to enhance the identification of high health risk patients and training health care providers to use these new technologies in the course of delivering care. Colorado’s infrastructure investments build on the existing Quality Health Network (QHN) platform, a health information exchange system that provides services to more than 600 western Colorado providers in a 40,000 square mile region. The Beacon funding is helping QHN add new data sources, develop a regional data platform to aggregate and normalize data from disparate sources, and deploy new high-value applications that foster community-wide interoperability. These applications will focus on delivering usable information to clinicians at the point of care and enabling broad-based population health management, care coordination, and cost-trend management.</p>
<p><b>Crescent City Beacon Community*</b></p>	<p>The Crescent City Beacon Community focuses on reducing the burden of diabetes and cardiovascular disease by working with many of the hospitals and safety net providers that serve New Orleans residents. The community’s key strategies include implementing a shared health IT solution for community-wide exchange of information, collecting data for population health management, and connecting to state and national information sources. Over the course of 2012, Crescent City successfully launched its health information exchange infrastructure, the Greater New Orleans Health Information Exchange (GNOHIE), including a clinical data repository, community master patient index, provider directory, secure direct messaging capabilities, and a data warehouse to support advanced analytics and reporting. Today the exchange connects 28 safety net clinics and two hospitals, with further expansion planned.</p>

Beacon Community	Overview
<b>Delta BLUES Beacon Community*</b>	The Mississippi Delta, one of the most disadvantaged regions in the nation, is also one of the unhealthiest, with a high prevalence of diabetes and a severe shortage of primary care and specialty providers. The Delta BLUES Beacon Community is fostering health information exchange through a partnership with the state Mississippi Health Information Network (MSHIN). Under Beacon, Delta BLUES has connected four hospitals, 11 clinics representing more than 30 sites, and four labs to MSHIN.
<b>Greater Cincinnati Beacon Collaboration</b>	The Greater Cincinnati Beacon Collaboration serves parts of Ohio, Kentucky, and Indiana and has sought to strengthen its existing HIE capabilities to accelerate multiple community programs and aims within a broader health care transformation agenda. An early adopter of community information exchange through Cincinnati-based HealthBridge, the community's quality improvement efforts have in part been driven by Fortune 500 employers seeking health care cost-containment strategies. The region's payers, hospitals, providers, and consumers also have been active in its health IT and quality improvement efforts. The Greater Cincinnati Beacon Collaboration used HealthBridge's existing HIE infrastructure to create and deploy admission, transfer and discharge (ADT) alerts. Aimed at reducing preventable emergency department (ED) visits and readmissions, HealthBridge provides automated notifications to primary care practices when patients with diabetes or asthma have an ED or inpatient visit. Since implementing ADTs, the 87 primary care practices and two post-acute providers have received more than 27,000 alerts from 21 participating hospitals.
<b>Greater Tulsa Health Access Network Beacon Community*</b>	The Greater Tulsa Health Access Network Beacon Community has created a robust health information exchange, MyHealth Access Network, to support community-wide care coordination, patient engagement, and quality improvement through services including referral management, a patient portal, business intelligence and analytics capabilities, care gap analysis, and individualized patient risk assessments. Additionally, MyHealth offers single sign-on and context management technologies, and a master patient index of more than 2.4 million patients.



Beacon Community	Overview
<p><b>Rhode Island Beacon Community</b></p>	<p>An early adopter of the patient-centered medical home model in smaller physician practices, Rhode Island boasts a history of provider/payer collaboration and proactive quality improvement efforts. Yet despite this environment, the perceived expense and complexity of facilitating health information exchange between practices and health systems deterred broad provider participation in the state’s information exchange solution, CurrentCare. Rhode Island Beacon Community focused on developing an “infrastructure-light” solution to achieve interoperability between CurrentCare and practice EHR platforms. The Rhode Island Beacon Community is also engaging 84 nursing homes across the state to become enrollment partners and users of CurrentCare by providing stipends for the purchase of computer systems and offering best practices training around patient enrollment and HIE.</p>
<p><b>San Diego Beacon Community*</b></p>	<p>San Diego County boasts a diverse urban population of more than 3 million residents. Within a robust marketplace of competing health plans, health systems and providers, the region has advanced EHR capabilities and health IT infrastructure in many key hospital systems. Even so, the community lacked a community-wide HIE system and had low EHR adoption rates in clinics that were not part of a larger network. The San Diego Beacon Community is developing local HIE capabilities that will enable providers to access patient records across the metropolitan area. As of July 2013, four hospital-based health systems and four medical groups are exchanging data. More than 447,145 unique patients can have their medical records accessed in an emergency. As of May 2013, over 124,000 patients have consented to sharing their medical records for clinical encounters.</p>
<p><b>Southeast Minnesota Beacon Community*</b></p>	<p>The Southeast Minnesota Beacon Community has a sophisticated health care landscape that includes four major medical systems, including the Mayo Clinic, and significant adoption of health IT. The Southeast Minnesota Beacon Community is implementing national IT standards to connect these major health system partners and public health departments in participating Beacon counties. These connections allow health care professionals to quickly access valuable information about a patient from multiple providers and provide public health nurse case managers with timely information to support transitions of care. Southeast Minnesota has also established a clinical data repository that enables evaluation and analysis of population level health status across the region regardless of where a patient accesses care.</p>

Beacon Community	Overview
<b>Western New York Beacon Community</b>	The Western New York Beacon Community is a partnership between a well-established regional HIE platform (HEALTHeLINK) and a number of local provider stakeholders. Under Beacon, HEALTHeLINK has added a significant number of new hospitals, long term care, and home health facilities as data sources. HEALTHeLINK also developed innovative new services such as a medication history capability that delivers electronic discharge medication lists from hospitals and ordered medications from long-term care/rehab facilities to primary care providers. Today, HEALTHeLINK data sources cover over 95 percent of the hospital beds in the region, with 95 percent of lab reports and 85 percent of radiology reports flowing into the HIE.

*\*Used Beacon Community funding to initiate the establishment of HIE capabilities in the region.*

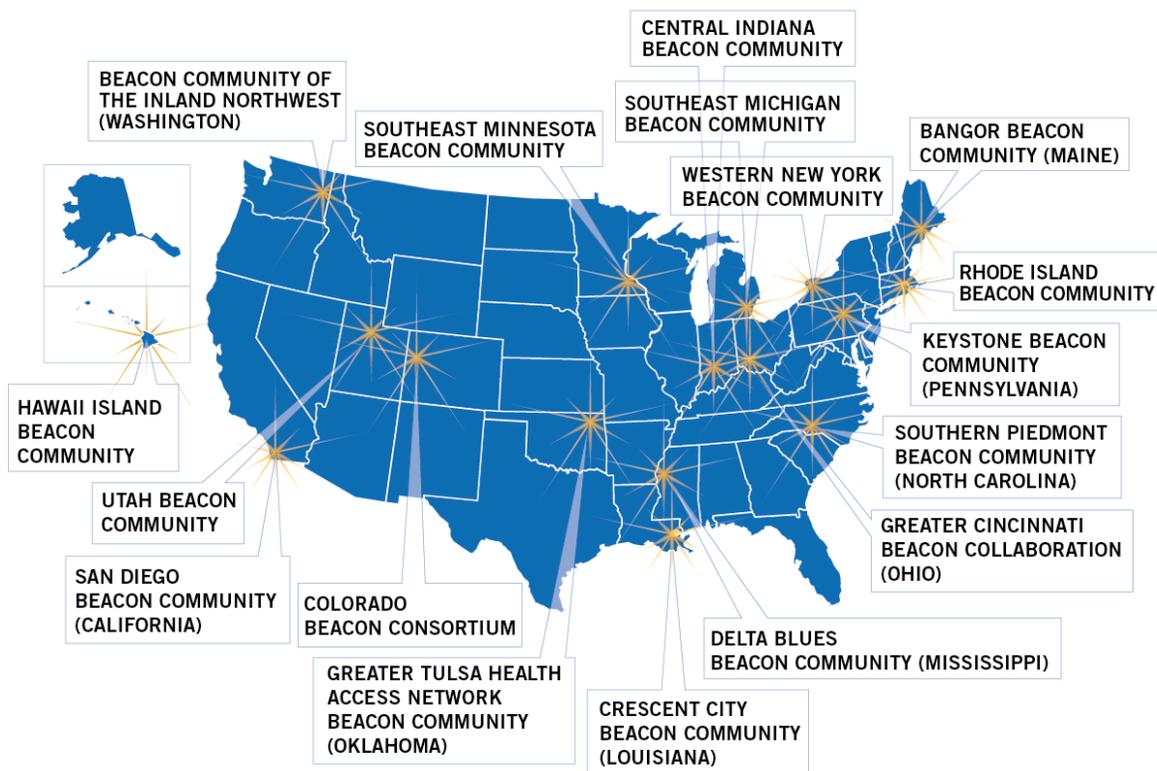
Collectively, the Beacon Communities touch close to eight million lives, interacting with more than 7,600 individual or practice-based physicians, 176 hospitals, and 28 payers. Partners also include more than 80 Federally Qualified Health Centers or community health clinics. Beacon Communities exist in a wide range of markets, including those with integrated health care delivery systems and those with loosely organized practices and hospital systems. Although Beacon Communities with integrated systems have advantages (e.g., aligned financial incentives, organizational objectives), communities with a history of collaboration (e.g., working to develop population health improvement program) were also well positioned to take on the goals of the Beacon Community program.

For example, led by Mayo Clinic, the Southeast Minnesota Beacon Community is collaborating with participating hospitals, clinicians, and public health entities to share key clinical information, including asthma action plans, across 11 counties in its region. Although there was an established health information organization (HIO) in the community, the lead convening entity and key stakeholders determined that a lightweight exchange infrastructure using peer-to-peer networking and national standards, such as CONNECT, would better serve the needs and goals of the community. In contrast, the Delta BLUES Beacon Community, led by the Delta Health Alliance (DHA), did not have established HIE capabilities in the Delta region. DHA contracted with Mississippi Health Information Network (MS-HIN, the state-designated HIE) and the state’s HIE vendor to provide exchange services to providers in Mississippi’s Delta community. By building upon existing work and infrastructure, DHA was able to achieve exchange goals while avoiding unnecessary spending. The Greater Tulsa Health Access Network Beacon Community in Tulsa, Oklahoma, provides yet another example. This Beacon Community decided early on that community-based analytics would be a key aspect of its exchange. Exchange capabilities did not exist in Tulsa, so the stakeholders agreed to build a community-based exchange. To fulfill the vision of community applications being built on top of a layer of clinical data, Tulsa selected a central repository model using query-based exchange capabilities. This model allowed Tulsa to aggregate data from multiple data sources and provide tools for clinicians and other involved in care delivery to access the information. These three Beacon Communities illustrate only a few of

the many HIE models that a community can pursue given its goals for data exchange, existing infrastructure, and history and experience in working collaboratively to improve health care.<sup>x</sup>

The Beacon Communities' experience provides a number of instructive examples of HIE initiatives focused on improving health outcomes in a given region, increasing the efficiency of care delivery, and preparing for future payment reform initiatives. Exhibit 3 shows the geographical distribution of all of the Beacon Communities, each of which have experience in developing or expanding health information exchange capabilities in their region.

*Exhibit 3: Beacon Communities*



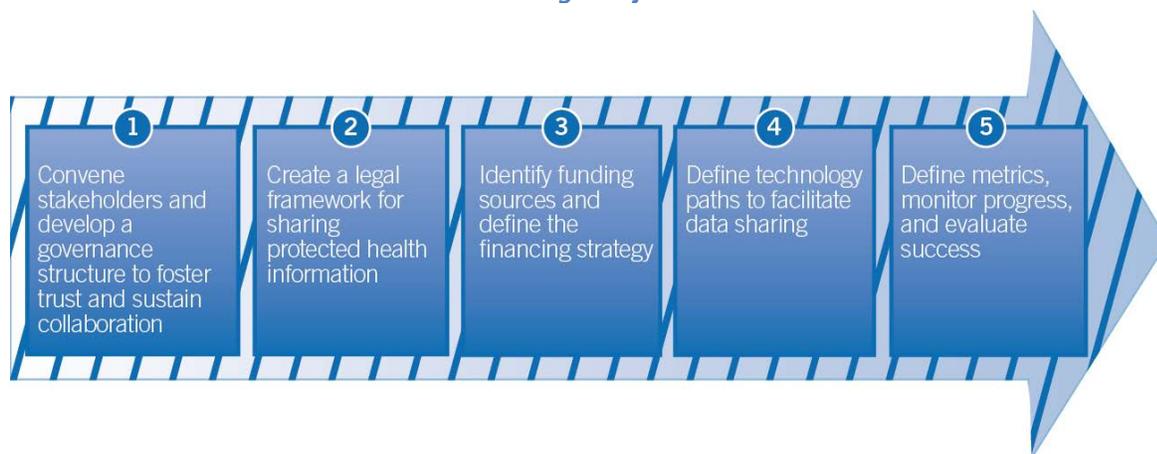
## Proven Strategies to Enable HIE in Achieving Community Health Goals

The material in this Learning Guide is synthesized into five Strategic Objectives (see Exhibit 4). The Learning Guide offers strategies from the Beacon Communities on topics such as legal and policy framework development, funding and financing strategies, technology assessment and selection, and ongoing evaluation and monitoring. The Strategic Objectives may happen in parallel and should not be read as sequential; community leaders may need to undertake multiple planning activities at once and iteratively refine and improve each strategy as further experience is gained.

Each Strategic Objective is described in detail in the following sections and is illustrated with the experiences of the Beacon Communities and other notable HIE efforts across the country. Each Strategic Objective section concludes with key considerations for decision makers and they are summarized within Exhibit 4. The Strategic Objectives for the *Enabling Health Information Exchange to Support Community Goals* Learning Guide include:

- **Strategic Objective 1:** Convene Stakeholders and Develop a Governance Structure to Foster Trust and Sustain Collaboration.
- **Strategic Objective 2:** Create a Legal Framework for Sharing Protected Health Information.
- **Strategic Objective 3:** Identify Funding Sources and Define the Financing Strategy.
- **Strategic Objective 4:** Define Technology Paths to Facilitate Data Sharing.
- **Strategic Objective 5:** Define Metrics, Monitoring Progress, and Evaluate Success.

*Exhibit 4: Strategic Objectives*



### Strategic Objective 1: Convene Stakeholders and Develop a Governance Structure to Foster Trust and Sustain Collaboration

The first Strategic Objective is fundamentally about building trust through collaboration with stakeholders, potential partners, and other interested parties from the outset. Each community will have its own unique actors; market dynamics; regulatory, political, and other environmental

factors; and its own history of collaborative efforts. Developing HIE capabilities requires collaboration among entities – such as payers, hospitals and health systems, and community providers – that may have historically distrusted one another and have competing interests. Reluctance to share information, especially among competing health care providers, can significantly impede HIE development.<sup>xi</sup> Beacon Communities’ experiences and chosen strategies were shaped by their immediate markets, stakeholders’ key interests, and communities’ capacity to sustain collaboration. This section describes practical insights related to:

1. Key market dynamics and environmental considerations.
2. Strategies for convening stakeholders and other interested parties.
3. Attributes of a governance structure that sustain collaboration among stakeholders.

### **1.1 Key Market Dynamics and Environmental Considerations**

The community’s market and political environment may be complex, requiring the lead convening entity to understand the motivations that will bring stakeholders to the table. These motivations vary, and success begins with recognizing the dynamics among stakeholders, the market in which they operate, and the lessons learned from past or ongoing collaborative efforts. From a market perspective, one health care system may carry a great deal of negotiating power because it is unique and lacks a clear competitor in the same geography. In other communities, health systems, medical groups, and providers may be aggressively competing for patient volume, higher reimbursement rates, or favorable contractual arrangements from payers. Past and ongoing collaborative efforts among stakeholders may also provide a base on which to build data exchange activity. Finally, past experience with health information exchange efforts in the region or state may provide energy for a new initiative or impede progress due to perceived risk of failure.

This section shares insights on:

- Achieving collaboration in a competitive environment.
- Building on collaborative efforts.
- Defining the purpose for data exchange.

#### ***Achieving Collaboration in a Competitive Environment***

In a competitive environment appropriate mitigating strategies can be developed to level the playing field and improve transparency and trust, thereby increasing the chance for a community to build sustainable governance and financing solutions for information exchange. Beacon Communities in highly competitive markets found that establishing a neutral third party to manage data exchange and the supporting core infrastructure can address concerns among participants.<sup>xii</sup> In San Diego, where several large hospital systems compete for market share, the San Diego Beacon Community ultimately transitioned to an independent, nonprofit entity, the San Diego Regional Healthcare Information Exchange, to enable data sharing across competitive boundaries and with independent health care providers. The new organization has successfully partnered with major players in the area, including Sharp Healthcare, Scripps Health, Kaiser Permanente, Children’s Primary Care Medical Group, the Veterans Administration, the University

of California, and 13 of the 16 regional community clinics, according to Executive Director Dan Chavez.<sup>xiii</sup>

The Bangor Beacon Community brought together and strengthened the relationship between HealthInfoNet and Eastern Maine Healthcare Systems (EMHS), two organizations that previously worked independently to improve care through the use of health IT. EMHS, the lead awardee in Bangor, and the largest health care system in Maine, already had a strong history of EHR adoption in inpatient and outpatient settings. Prior to receiving Beacon Program funding, HealthInfoNet had successfully connected four large Maine health systems, an independent rural hospital, and a large primary care group. The Bangor Beacon Community chose to focus on enhancing and expanding upon the community's existing health information exchange's efforts piloted by HealthInfoNet. Since stakeholders had decided to build upon an existing infrastructure, decisions made by community stakeholders prior to the Beacon program had a direct impact on the future direction of the data exchange strategy. Dev Culver, CEO of HealthInfoNet, reflected that the organizations that came together to pilot HealthInfoNet (including EMHS) were not interested in competing with each other based on access to patient data (i.e., using access to other organizations' data to entice their patients and grow market share). Instead, competition was based on breadth of patient services, quality of care, and patient experience. Deciding from the start that information sharing would not be used to gain competitive advantage was an important guiding decision when the Bangor Beacon brought the stakeholder community together to build on its data exchange strategy.<sup>xiv</sup>

Participating entities of the Southern Piedmont Beacon Community in North Carolina arrived at similar conclusions: they decided not to compete with each other based on access to patient data and to strengthen the community's existing health IT infrastructure as they developed the data exchange strategy. When Southern Piedmont initially received the Beacon Community award, it considered establishing a central community-wide HIE capability. However, rather than opting to share data directly with one another, Stanly Regional Medical Center, Rowan Regional Medical Center, and the Carolinas Medical Center-Northeast (CMC-NE, a Carolinas HealthCare System hospital) decided to build upon the efforts of a neutral party, the Informatics Center of the Community Care of North Carolina (CCNC). CCNC Informatics Center already collected and analyzed claims data for North Carolina's Medicaid population, and incorporating clinical data from area hospitals both strengthened the existing infrastructure and enabled its expansion. As part of this effort, interfaces between Southern Piedmont hospitals and the Informatics Center were also able to be activated statewide. For example, developing the connection for one of the 33 hospitals that are part of the Carolinas HealthCare System means that the connectivity is in place for all 33 of the hospitals to ultimately send data to connect to the CCNC Informatics Center.<sup>xv</sup>

### *Building on Collaborative Efforts*

For communities that have already established a process or body to bring together potential competitors to address health care needs, building on those collaborative efforts can be a more expeditious strategy. For example, rather than focusing on a new exchange solution for the Mississippi Delta, the Delta BLUES Beacon Community looked to the emerging state health information network, Mississippi Health Information Network (MS-HIN) as a way to deploy information exchange for Delta providers. The Delta Health Alliance (DHA), lead grantee for the

Beacon Community, already had an alliance of key stakeholders with a history of working together on the region's health care problems, as well as a number of clinics for which it provided a hosted EHR solution. DHA was well positioned to convene these stakeholders and clinic partners to build interfaces to the state solution. Delta BLUES has now connected four hospitals, approximately 30 practice locations, and four labs to MS-HIN<sup>xvi</sup>

The lead awardee of the Crescent City Beacon Community, the Louisiana Public Health Institute, focused on building on the long-standing relationships among the community's safety net providers to establish the Greater New Orleans Health Information Exchange (GNOHIE). After the damage caused by Hurricane Katrina in 2005, public health and community leaders began to consider a framework that would "support a vision of a more patient-centered and effective health sector."<sup>xvii</sup> The safety net providers made strides in developing patient-centered medical homes and were called a national model by HHS Secretary Kathleen Sebelius, especially in their efforts to integrate primary care and mental health services, improve care coordination and population health analytics, and create new payment models to support team-based, innovative primary care services. The Crescent City Beacon Community built on the community's commitment, experience, and momentum around successful health IT efforts to reach a consensus on the need for improved care coordination and then developed infrastructure through GNOHIE to help stakeholders pursue those goals. Today, relevant GNOHIE capabilities include community-wide disease registries, an electronic specialty referral system, and notifications of emergency department or inpatient encounters to a patient's primary care provider.

The success of the GNOHIE can be attributed to several factors. First, the community stakeholders were involved at a very early stage to provide input into the clinical transformation goals and scenarios that would be best supported by health information exchange. Second, while all community stakeholders were involved in the initial planning phases, Beacon leadership made a deliberate decision to encourage providers to join the local exchange effort based on their readiness and goal alignment, and supported others to connect through the state HIE platform where appropriate. Currently, the GNOHIE is connected to 24 primary care practice sites and two hospitals, with plans to connect to additional primary care practices, specialists, and hospitals.

### *Defining the Purpose of Data Exchange*

Clearly articulate the practical reasons for why HIE capabilities are needed will foster engagement with the community, help facilitate buy-in from key stakeholders, and ultimately drive commitment from all levels of the participating organizations, including those responsible for implementation and the end users of the data. Additionally, defining the purpose of data exchange will help define the different stakeholders who need to have a seat at the table. For example, if improving transitions of care to and from hospitals becomes a priority, leadership may want to include a broader set of partners such as community clinics, skilled nursing facilities and behavioral health providers. Exhibit 5 provides a few examples of why different stakeholders may be motivated to share data.

*Exhibit 5: Stakeholder Group and Examples of Their Motivation to Exchange Data*

Stakeholder Group	Examples of Stakeholder Motivation
<b>Hospitals and Health Systems</b>	<ul style="list-style-type: none"> <li>• Exchange admission, discharge, and transfer information between departments or facilities within the same hospital system or between systems to improve health care outcomes (e.g., facilitate care coordination, reduce avoidable hospitalizations or readmissions).</li> <li>• Exchange clinical data and administrative data to meet meaningful use requirements.</li> <li>• Transfer administrative and quality of care data to payers or the state for reimbursement.</li> <li>• Transfer or exchange data with contracted practices or medical groups to support quality reporting activities.</li> <li>• Transfer of data to payers to meet the requirements of payment reform programs (e.g., ACO arrangements or value-based contracts).</li> </ul>
<b>Provider Organizations, Primary Care Practices, and Specialists (including Federally Qualified Health Centers and FQHC-like centers)</b>	<ul style="list-style-type: none"> <li>• Exchange clinical and administrative data to meet meaningful use requirements.</li> <li>• Exchange of clinical and administrative data with other providers to improve coordination and outcomes.</li> <li>• Transfer administrative and quality of care data to payers or the state for reimbursement.</li> <li>• Transfer of data to payers to meet the requirements of payment reform programs (e.g., ACO arrangements or value-based contracts).</li> </ul>
<b>Public Health Agencies</b>	<ul style="list-style-type: none"> <li>• Receive data to conduct public health surveillance, such as immunization data or cancer registry information.</li> <li>• Access a centralized data repository to monitor population health and conduct population-based analytics.</li> <li>• Exchange information on patients receiving care or services from public health providers.</li> </ul>
<b>Long term care, post-acute care providers and other community-based providers (e.g., home health, skilled nursing, behavioral health, social services etc.)</b>	<ul style="list-style-type: none"> <li>• Exchange admission, discharge, and transfer information with hospitals and other care providers to improve transitions of care</li> <li>• Transfer administrative and quality of care data to payers for reimbursement.</li> <li>• Contribute to and query a central repository to support longitudinal care coordination</li> </ul>
<b>Patients or Consumer Advocacy Groups</b>	<ul style="list-style-type: none"> <li>• Ensure access to data to support consumer empowerment and activation.</li> <li>• Ensure privacy and security of personal health information.</li> <li>• Ensure equitable use of information to prevent discriminatory practices.</li> </ul>
<b>Labs and Diagnostic Centers</b>	<ul style="list-style-type: none"> <li>• Securely and reliably transfer lab orders and results, radiology reports, and other diagnostic reports to the point of care to support clinician in recommending treatment options.</li> <li>• Monitor and process undelivered messages.</li> </ul>

Stakeholder Group	Examples of Stakeholder Motivation
<b>Payers and Pharmacy Benefit Managements</b>	<ul style="list-style-type: none"> <li>• Exchange patient-specific information that includes benefit coverage, formulary, prescription history, authorizations, and eligibility verification for reimbursement.</li> <li>• Exchange Healthcare Effectiveness Data and Information Set (HEDIS) reporting for quality of care measurement.</li> <li>• Receive quality of care and access measurement data from contracted providers for pay for performance.</li> </ul>
<b>State Medicaid</b>	<ul style="list-style-type: none"> <li>• Exchange of electronic claims and eligibility information with the state HIE.</li> <li>• Receive data from Medicaid providers to monitor quality and access to care.</li> </ul>
<b>Purchasers and Employers</b>	<ul style="list-style-type: none"> <li>• Exchange of patient and employee wellness information and family history reports to potentially lower insurance costs and improve employee health.</li> </ul>
<b>Lead Convening Entity, HIOs, or State HIE Organization</b>	<ul style="list-style-type: none"> <li>• Ensure data exchange governance structure, policies, and procedures meet Federal and state requirements.</li> <li>• Transfer of data to disease registries (i.e., to ensure patient vaccinations are up to date).</li> <li>• Maintain a community master patient index to ensure there is consistent, accurate, and current demographic and essential patient data.</li> </ul>
<b>Other Community Stakeholders</b>	<ul style="list-style-type: none"> <li>• Quality improvement organizations use information from a clinical data repository (CDR) to design evidence-based quality improvement initiatives.</li> <li>• Regional associations, such as local specialty societies or the regional medical associations, ensure membership are trained and equipped to meet meaningful use requirements; work with membership to sustain health IT and HIE infrastructure improvements.</li> </ul>

Sources: Adapted from eHealth Initiative. HIE Toolkit available at: <http://www.ehidc.org/hie-toolkit/setting-up-a-governance-structure/stakeholders-roles-needs>. Accessed on June 9, 2013.

## **1.2 Strategies for Convening Stakeholders and Other Interested Parties**

Convening stakeholders to reach consensus, articulate a shared vision, and deliberately define the clinical transformation goals for data exchange requires well-vetted strategies. Based on the experiences of Beacon Communities and other health information organizations, this section describes practical insights on:

- Convening strategies to promote transparency and consensus.
- Using champions and opinion leaders.
- Developing a shared vision, mission, and goals for HIE efforts.
- Developing real-world scenarios to articulate how the community can achieve clinical transformation goals.

### ***Convening Strategies to Promote Transparency and Consensus***

By engaging in strategies that are open, transparent, democratic, and consensus-driven, communities can promote and sustain collaboration among key stakeholders. The Greater Tulsa Health Access Network Beacon Community (Tulsa) found that building a culture of collaboration and trust was perhaps the most important ingredient for success and emphasized that there were no shortcuts for fostering that trust. For example, when Tulsa Beacon leaders first convened interested parties within the community, they brought together a diverse group of stakeholders, including hospitals, providers, payers, public health agencies, clinical laboratories, pharmacies, radiology centers, and other providers. At the beginning of each meeting, Tulsa engaged in a level-setting strategy, providing public health statistics (e.g., mortality rate trends for the under-65 population) that demonstrated the vast potential for health outcome improvements that could result from the community's collective efforts. In addition, the needs and potential value of data exchange for each stakeholder group was articulated and discussed. This level-setting strategy served multiple purposes:

- It grounded the convening aims in improving clinical and public health outcomes versus investing in health IT for its own sake.
- It reinforced the value proposition and addressed the “why are we here” question for each stakeholder group.
- It fostered transparency and continuity, allowing individuals who participated at various points of the process to get up to speed and actively engage.
- It made explicit that the stakeholders had clearly aligned goals with more commonalities than differences – especially when taking a long-term and community-wide view.

### ***Use of Champions and Opinion Leaders***

In many instances, Beacon Communities accessed the influence and credibility of opinion leaders willing to devote the time and energy to champion the potential benefits of exchange solutions. Tulsa attributes the momentum and credibility established during the early phases of the data exchange initiative in part to the mayor's office. In June 2009, Mayor Kathy Taylor invited health care providers to “join forces in the Greater Tulsa Health Access Network project, to work

collectively toward improving the quality of care for residents...and further public and private partnerships for the development of an electronic health information infrastructure...that provides needed information at the point of patient care.”<sup>xviii</sup> Her announcement and support through the next few months gave Tulsa immediate credibility among the various health care organizations and stakeholder groups engaged in the HIE capability development effort.

Each organization or stakeholder group can benefit from having its own champion working to achieve buy-in across the community while simultaneously representing its organizational interests. It is vital to identify physician champions who command the authority and respect of other physicians to make the value case to community practices, hospitals and health systems, and other clinicians.

In southeastern Minnesota, the Mayo Clinic and Mayo Clinic Health System were considered natural conveners and leaders in the market. However, early on they promoted the concept of equal partnership among all stakeholders, including Olmsted Medical Center and Winona Health Services, and Allina Health. Each stakeholder was aware that data sharing and cooperation was necessary to obtain a full picture of an individual patient and his or her health care use (e.g., primary and specialty care) and a full picture of the population (e.g., key public health indicators). A guiding principal in developing HIE governance and structure was the notion that “Beacon is clearly not about any single entity or organization, but about the patients and the families being served.”<sup>xix</sup> The lead convening entities’ role in promoting equal partnership was key in driving a culture of true collaboration, equal participation, and shared accountability in the Southeast Minnesota Beacon Community.

#### *Developing a Shared Vision, Mission, and Goals for Exchange*

Beacon Communities have emphasized the importance of working as a community to articulate a shared vision for HIE efforts from the onset. A vision statement is typically an aspiration description of what an organization would like to achieve or accomplish. A mission statement is specific to the organization and describes specifically why the organization exists and how it intends to demonstrate value to its stakeholders. The process of developing a shared vision and mission can help all stakeholders understand where their interests intersect and where there is common ground, providing a focal point around which goals, policies, financing, and an evaluation plan can be developed. Exhibit 6 provides vision and mission statements related to data exchange initiatives initiated or enhanced as part of the Beacon Community program.

*Exhibit 6: Beacon Community Vision and Mission of HIE Initiatives*

HIO/Beacon Community	Vision and Mission Statements
<p>Quality Health Network (QHN)</p> <p><b>Colorado Beacon Consortium</b></p>	<p>QHN is a nonprofit dedicated to health care quality improvement. QHN was created to improve the health of people who live across western Colorado.</p> <p>Mission: To facilitate the availability of information to optimize the health of our communities, improve economic efficiencies of patient care, and bring value to our stakeholders.</p> <p>Source: <a href="http://qualityhealthnetwork.org/about">http://qualityhealthnetwork.org/about</a></p>
<p>HEALTHeLINK</p> <p><b>Western New York Beacon Community</b></p>	<p>HEALTHeLINK, a nonprofit organization, is an unprecedented collaboration among Western New York physicians, hospitals, and insurance organizations to share clinical information in efficient and meaningful ways to improve the delivery of care, enhance clinical outcomes, and control health care costs throughout the region.</p> <p>Mission: To create and maintain a secure and reliable infrastructure for the timely and accurate electronic exchange of clinical information among health care providers, insurers, and other medical professionals.</p> <p>Vision: For Western New York to have an electronic system for real-time sharing of clinical information among health care professionals to promote collaboration; limit duplication; control health care costs; and improve the delivery of services, clinical outcomes, and patient safety.</p> <p>Source: <a href="http://wnyhealthelink.com/AboutUs/Mission">http://wnyhealthelink.com/AboutUs/Mission</a></p>
<p>Greater New Orleans Health Information Exchange (GNOHIE)</p> <p><b>Crescent City Beacon Community</b></p>	<p>GNOHIE is a community-shared health IT infrastructure that enables care coordination and chronic conditions management across health systems in the Greater New Orleans area.</p> <p>GNOHIE is focusing initially on two objectives: (1) ensuring patients receive timely, seamless care across clinical settings by notifying primary care providers when one of their patients is admitted or discharged from the hospital and (2) by facilitating referrals between primary care providers and specialists.</p> <p>Sources: <a href="http://lphi.org/home2/section/2-22-119/positions-available/view/296/">http://lphi.org/home2/section/2-22-119/positions-available/view/296/</a>  <a href="http://www.healthit.gov/sites/default/files/beacon-factsheet-cc-nola.pdf">http://www.healthit.gov/sites/default/files/beacon-factsheet-cc-nola.pdf</a></p>

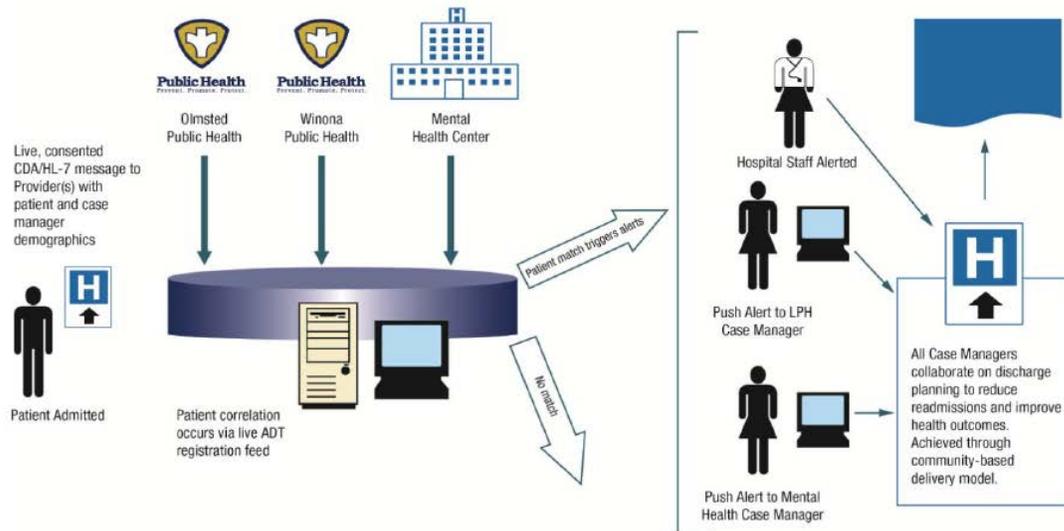
HIO/Beacon Community	Vision and Mission Statements
<p>San Diego Regional Healthcare Information Exchange</p> <p><b>San Diego Beacon Community</b></p>	<p>The San Diego Regional Healthcare Information Exchange is a partnership of health care providers, clinics, hospitals, emergency medical services, and public health organizations.</p> <p>Mission: To improve the health of our community through collaborative sharing of information supported by technology.</p> <p>Vision: To provide the right information to the right person at the right time to improve health.</p> <p>Source: <a href="http://www.sandiegobeacon.org">http://www.sandiegobeacon.org</a></p>

***Developing Real-World Scenarios to Articulate How the Community Can Achieve Clinical Transformation Goals***

Once the vision, mission, and goals are established, stakeholders can continue to work together to identify clinical priorities and clearly identify those scenarios detailing how information exchanges will drive clinical transformation. Through these scenarios, stakeholders are able to see how the information will flow, who will contribute data, who will use the data, how the clinical workflow changes, and how the patient is directly affected. Through that process, they are able to vet underlying assumptions regarding current practice and desired goals. These clinical scenarios should be designed such that administrators, clinicians, IT, and systems staff can have a starting point to communicate the current state and desired state, post-implementation. Clearly defined scenarios can be a basis for the development of technical use cases during the implementation phase.

Southeast Minnesota decided to address readmissions through an ADT alerting initiative to notify the appropriate community case managers or care coordinators when a patient is hospitalized. As illustrated in (Exhibit 7) below, such alerting enables case managers to begin patient-centered discharge planning early in a patient’s hospital stay.

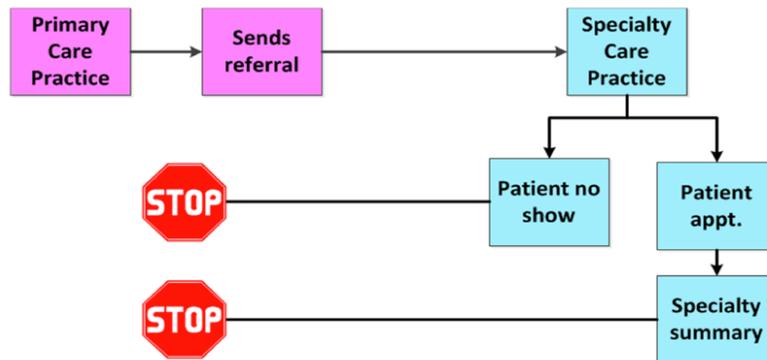
*Exhibit 7: Southeast Minnesota Exchanges Data to Enable Public Health Case Managers to Work with Patients to Reduce the Risk of Readmission*



Crescent City Beacon Community focused on addressing care coordination between primary care practices and specialty care. Specifically, it wished to use health information data exchange to enable the primary care practice to be notified when a patient does not follow through on a referral to a specialist; when a patient makes an appointment with a specialist and when that appointment occurs. In addition, the specialist’s consult summary would be provided to the primary care practice to ensure the primary care provider had complete information. (Exhibit 8) below illustrates how the implementation of the Electronic Specialty Referral System was intended to enable data exchange and information flow from specialty care to the primary care provider.

*Exhibit 8: Crescent City Beacon Community Exchanges Data to Enable Primary Care Providers to Be Notified of a Patient’s Specialist Appointment, Appointment Occurrence, or No-Show and to Obtain Patient Summaries Following Specialists’ Visits*

## Pre-Electronic Specialty Referral



### Addressing Patient Safety for Cardiac Patients at the San Diego Beacon Community



The San Diego Beacon Community focused its health information exchange efforts to improve patient safety for cardiac patients before they enter the emergency department (ED). San Diego implemented a mobile wireless technology to help first responders improve patient care by equipping them with mobile EKG devices. When a patient calls with symptoms of chest pain, first responders are able to perform a 12-lead EKG to determine if the patient is having a heart attack. The EKG is transmitted to eight base stations in the county, run by a hospital ED, where nurses help to guide paramedics. The EKGs, readable on smartphones and mobile devices, can be sent to the nurses, ED, and cardiologists regardless of their location. The program has improved patient safety and cost benefits by reducing the number of emergency activations of cardiac intervention teams based on false-positive results from the first responders’ EKG devices. The false-positive rate has dropped from 30 percent to 0 percent, saving 10 to 15 patients a month from the risk and discomfort of undergoing unnecessary cardiac interventions and sparing hospitals from the cost of activating cardiac teams.

Expanding its efforts to incorporate HIE in improving patient safety, the San Diego Beacon Community is also focusing on improving care for patients who repeatedly access 911. For this population, providing repetitive transportation to EDs is ineffective and wasteful of 911 resources, while leaving the underlying need unaddressed. Through the Beacon Community program, San Diego has demonstrated significant value in the bidirectional information exchange between EMS and hospitals. This has led to an improved eRAP (electronic Resource Access Program) to act as an electronic surveillance and case management platform to continuously monitor incoming electronic patient care reports (ePCR) and computer-aided dispatch (CAD) information. The goal is to display a real-time comprehensive status of repeated

911 activity, including the use of individual patients on operations and resources over time (e.g., past week, past year). This tool allows coordinators to prioritize and strategically deploy resources to improve the effectiveness of interventions.

### **1.3 *Attributes of a Governance Structure that Sustain Collaboration among Stakeholders***

Implementing an appropriate governance structure can promote the inclusion, transparency, and engagement needed to sustain trust and collaboration among stakeholders participating in exchanging data. The governance structure needs to include formal channels for stakeholders to have meaningful input on a wide range of design issues. Governance considerations include the level of information sharing, and the design of the technology solution. For example, communities implementing secure messaging between providers will face different considerations from those that wish to establish a centralized data repository. This section will describe attributes of a governance structure that can lead to successful and sustained collaboration, specifically:

- Principles and a governance framework that can be used to guide the efforts of a community when establishing the corporate structure and governing board, as well as the efforts of the governing board once it is established.
- Considerations for establishing a corporate structure appropriate for the community.
- Practical insights for establishing a governing board and governing process.

#### ***Adhering to Guiding Principles***

As a practical measure, implementing a culture of inclusion, transparency, and engagement to ultimately achieve trust and sustained collaboration over time requires a commitment at the leadership level to adhere to certain guiding principles. ONC's Governance Framework (see Exhibit 9) promotes principles of organizational transparency and openness while emphasizing the importance of establishing policies and technical capabilities to safeguard privacy and security. These guiding principles are useful for establishing the appropriate corporate and organizational structure and establishing the governing board structure and process. For example, the organizational principle for inclusion would guide a community in selecting a diverse and representative set of members for the governing board. Once a governing board is established, the same principle promotes stakeholder representation and engagement (especially among patients and their advocates) in the development of policies.

*Exhibit 9: The Governance Framework for Trusted Electronic HIE*

ONC's Governance Framework consists of four guiding principles on HIE governance:

- **Organizational principles:** transparency and openness, inclusiveness, oversight and enforcement.
- **Trust principles:** meaningful choice to participate in HIE, limited types of data exchange, transparency in privacy and security practices, and accuracy of information.
- **Business principles:** open access and standards to promote collaboration.
- **Technical principles:** technology that can accommodate exchange through the use of standards and implementation specifications, testing, and collaboration with voluntary consensus standards organizations.

Source: Adapted from the *Governance Framework for Trusted Electronic Health Information Exchange*. Available at: [http://www.healthit.gov/sites/default/files/GovernanceFrameworkTrustedEHIE\\_Final.pdf](http://www.healthit.gov/sites/default/files/GovernanceFrameworkTrustedEHIE_Final.pdf). Accessed on June 9, 2013.

*Establishing a Corporate Structure*

If a new entity is being created to support community-wide HIE work, establishing a corporate structure is necessary to legally assign governance, fiduciary, and oversight responsibilities and to hold participating entities accountable for exchanging data. Potential options for HIE corporate structures are described in Exhibit 10. These options are not all mutually exclusive and can be selected based on the community's needs and goals, partner mix, and other factors relevant at the local or state level. Historically, regional, local, or state nonprofit or government-sponsored HIE models that would broadly support all providers in a community have driven the establishment of exchange. Today, large health systems and a variety of health IT vendors with capabilities to build data-secure storing, transfer, and analytic functions are working in some capacity to support establishment of exchange solutions.<sup>xx</sup>

*Exhibit 10: Health Information Exchange Corporate Structures*

Business Model	Description
<b>Not-For-Profit</b>	<p>These entities are driven by their nonprofit health care charter within the community for which they operate and provide services. Tax-exempt status and potential tax credits or incentives may assist such organizations in mitigating costs. An emerging variation to the not-for-profit model is the ability to use philanthropy to drive the sustainability of an HIE. This model is similar to how many hospitals operate today, as well as National Public Radio.</p> <p><i>Examples: San Diego Regional Health Information Exchange; Quality Health Network (Colorado)</i></p>
<b>Public Utility</b>	<p>These entities are created and maintained with the assistance of Federal and state funds that provide direction by Federal and state governments through laws, regulations, and grant requirements and obligations. This type of business model has tight fiscal controls, and funding sources can be limited given recent economic conditions.</p> <p><i>Example: Statewide Health Information Network for New York is coordinated by the New York eHealth Collaborative in conjunction with the New York State Department of Health</i></p>
<b>Physician and Payer Collaborative</b>	<p>While not explicitly a corporate structure, this collaborative organization is a potential business model created for or by payers and physicians for the strategic benefit within a region. Medical groups (and ACOs) are the ideal candidates for this type of HIE business model.</p> <p><i>Example: Monarch HealthCare in Orange County in collaboration with Anthem Blue Cross and Cal-e-Connect. Monarch is a Pioneer ACO.</i></p>
<b>For Profit</b>	<p>The for-profit entity is created with private funding and has a clear return-on-investment (ROI) strategy; it hopes to benefit from the medical and technology services it provides. A health care organization acting as a local application service provider hopes to benefit financially from its usually advanced systems by providing hosting services to less technically feasible groups for systems recordkeeping functions. Transaction-based fees or fee for services is a common sustainable funding approach for a for-profit organization.</p> <p><i>Example: The Indiana Health Information Exchange is spinning off a for-profit company to support its own efforts and bring the benefits of health information exchanges to other states and communities. The yet-to-be named entity target clients include health systems using or moving to the ACO model; fast growing health systems that want a private exchange; long-term care organizations that need to manage transitions of care<sup>xxi</sup></i></p>

Source: Adapted from Deloitte Center for Health Solutions. (2006). Health Information Exchange (HIE) Business Models: The Path to Sustainable Financial Success

### *Working with a Governing Board*

As discussed below, obtaining consensus on legal frameworks, data-sharing agreements or common policies and procedures can be especially challenging and resource intensive, given the level of liability and exposure each party has at stake. In working with governance boards to reach this consensus, Beacon Communities identified a number of principles for ensuring success.

- The governance board should be **representative** of all stakeholders that plan to contribute, use, or support HIE.
- Stakeholders should examine organizational goals and work to ensure **alignment with community-wide goals**.
- Stakeholders should establish processes for clear communication and **equal participation and accountability**.

Beacon Communities found that using workgroups or committees is a useful tactic to ensure participation and accountability. It also allows for deep-dive assessments and provides a forum for the governing board to receive advice on key issues, such as legal frameworks, data standards and interoperability issues, measurement and evaluation strategy, clinical standards and quality improvement, and financing strategy.

For example, a legal workgroup chaired by a privacy officer and made up of key stakeholder organizations' legal representation provides advice to the governing body about issues related to patient consent, as well as other matters. Each member of the workgroup communicates its organization's HIE goals and concerns to the workgroup. The workgroup first collaboratively develops a legal framework for HIE that is satisfactory to all stakeholders. Going forward, the workgroup continues to collaborate and advise the governing board on issues and concerns as related to that framework. Creating an environment where the key stakeholders and their legal counsel understand the community HIE goals and regularly collaborate, fosters a culture of transparency, openness, and trust.

The Maryland Chesapeake Regional Information System for our Patients (CRISP) – one of the premier regional HIE organizations in the country, connecting all hospitals in Maryland and providing patient hospital records, lab and radiology tests and medication history– echoed the Beacon Communities' perspective. CRISP believes that governance should be representative of the community's values and interests and structured to obtain useful and actionable advice from stakeholders. Maryland CRISP's governance structure is a board of advisors structured into four committees, including clinical, exchange advisory, finance, and small practice advisory. The board comprises various constituencies, including Erickson Living, The Johns Hopkins University, MedStar, and University of Maryland. A separate HIE Policy Board was also created to assist with instituting the various and evolving policies that govern HIE in Maryland.

### Greater Tulsa Health Access Network Beacon Community Governance Structure



In creating its governance structure, the Tulsa Beacon Community found that putting a culture of collaboration first has been its bedrock. Community members first convened to create a charter that committed all signees to participation in the planning process. Participants met to review materials and were brought up to speed on the HIE agenda. This ensured that each participant from various committees had an understanding of the Beacon Community goals and had the opportunity to provide input as part of the team. Partitioning the work into subcommittees allowed groups to simultaneously do a majority of the heavy lifting and research to advise the full body on recommended actions. As indicated by the following diagram, these subgroups included finance, human resources, communications, clinical and quality, privacy and security, community engagement, technology, and a participant council. The full body of the board of directors (a more than 19 member board) was composed to provide representation from a diverse group of stakeholders. This group is made up of representatives from health systems (6); clinicians (2); community Federally Qualified Health Centers, safety nets, and schools (2); private payers (2); universities (2); tribal organizations (2); patients (1); public health (1); and employers, funders, and patients (1).



Effective governance structures typically include bylaws that:

- Articulate that the governing body is ultimately responsible to the community it is serving and accountable for achieving the vision and goals for data exchange (further discussed under Strategic Objective 2).
- Define roles and responsibilities, including clarifying the roles and responsibilities of the governing board, individual workgroups, chair, officers, and members. The roles and responsibilities are best determined collaboratively so that all participants have the opportunity to weigh in on key decisions. The roles and responsibilities will include

fiduciary, legal, audit, reporting, and other governance requirements based on applicable Federal and state laws and other requirements (e.g., grant-based reporting requirements). Clarifying roles and responsibilities is particularly important to keep momentum during leadership transitions or when new members come in with specific expectations or agendas.

- Clarify how decisions are made. Establishing clear processes for decision making will promote transparency and accountability – so that each participant is motivated to play an active role. It can also help mitigate potentially problematic dynamics, for example, when a major organization is partially or minimally engaged.
- Specify terms and how members can be added or removed. Term length and limits are useful to set parameters and help ensure stakeholders have the opportunity to lead and make decisions on an equitable basis.

Finally, the governance structure can further promote transparency by offering opportunities for public engagement, for example, ad hoc input or focus groups, issue-specific surveys, or social media.

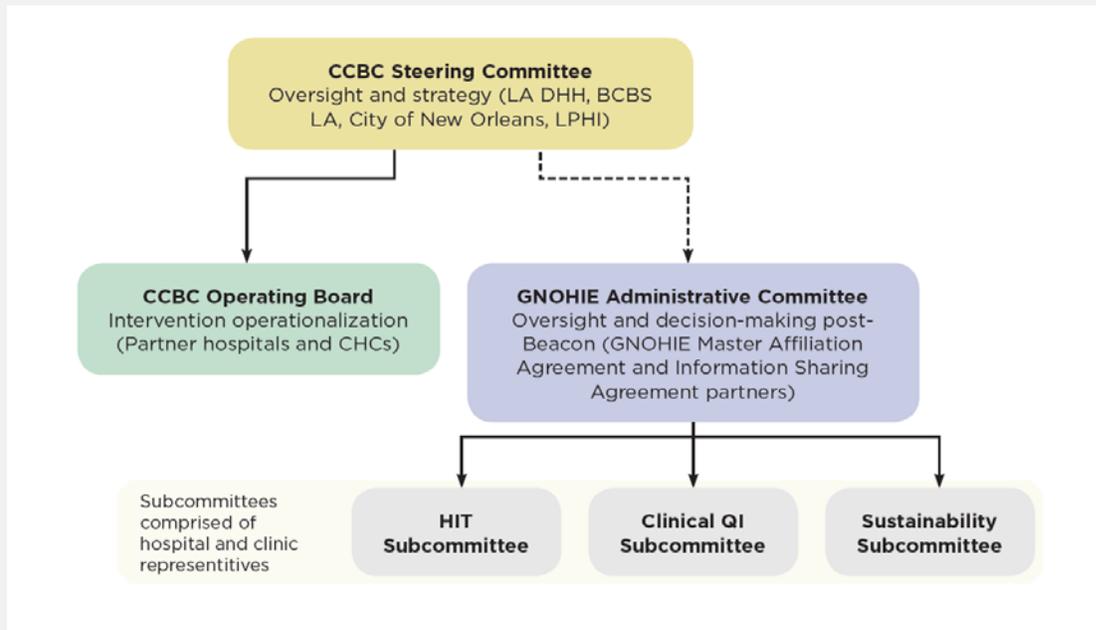
## The Crescent City Beacon Community: Governance Guiding Principles



The Crescent City Beacon Community found that three pillars are necessary among participating entities for successful and sustainable intervention implementation to occur:

- Trust
- Engagement
- Ownership and accountability

Active governance bodies led by invested community stakeholders are the primary vehicles by which trust, engagement, and ownership and accountability are established and maintained. The Crescent City governance structure, as depicted below, contains two components. One component includes the Crescent City Beacon Community Operating Board and Steering Committee, which have been active since the inception of the CCBC Initiative. The other component includes the GNOHIE Administrative Committee, which was formed in the first quarter of 2012 as the first step in creating a permanent governance structure to provide oversight and decision-making regarding Beacon-related interventions, activities, and infrastructure and continue strategic planning, sustainability, and GNOHIE adoption after the conclusion of the Beacon funding period.



Source: [http://www.crescentcitybeacon.org/uploads/media\\_items/ccbc-3rd-annual-report.original.pdf](http://www.crescentcitybeacon.org/uploads/media_items/ccbc-3rd-annual-report.original.pdf)

Governance is time-consuming and requires outreach, patience, and tenacity – communities and the governing body should expect to give considerable time to address these dynamics, as they are a normal part of developing HIE capabilities.

Key Considerations for the Lead Convening Entity and Governing Board	
<b>Lead Convening Entity</b>	
<ul style="list-style-type: none"> <li>• Who are the key stakeholders and what are their current relationships?</li> <li>• What strategies are needed to convene partners and stakeholders?</li> <li>• What stakeholder needs can be addressed by HIE?</li> <li>• Who are the champions that will commit time and energy to continuing development?</li> <li>• Will stakeholders come together to articulate, own, and generate support for the common vision?</li> <li>• Will stakeholders agree to the clinical transformation scenarios that they wish to work toward in the near term?</li> </ul>	
<b>Governing Board</b>	
<ul style="list-style-type: none"> <li>• What corporate structure should be established to best meet the community’s needs, to have the best chance of ensuring that participating entities are accountable for sharing data according to nationally established standards, and to provide financial sustainability?</li> <li>• What should the governance structures and processes to maintain ongoing collaboration look like?</li> <li>• How will stakeholders realize when their needs are met or value is realized?</li> </ul>	

## Strategic Objective 2: Create a Legal Framework for Sharing Protected Health Information

State and Federal laws and regulations govern the exchange of protected health information (PHI), and each participating entity and user bears significant legal responsibility for proper stewardship of the data. For example, Federal law governing PHI includes the Health Insurance Portability and Accountability Act (HIPAA), which includes provisions addressing security standards for health data, patient access to records, patient notification, and use of de-identified data. HITECH expanded HIPAA’s Privacy and Security Provision to include “business associates,” including HIE vendors and subcontractors handling PHI. HITECH also established new notification requirements if, for example, there is a breach of unsecured PHI. It also expanded accounting of disclosures of patient information for the purposes of treatment, payment, and health care operations.

Certain Federal regulations include additional privacy protections. For example, beneficiaries of federally-funded substance abuse programs have additional protections under the Confidentiality of Alcohol and Drug Abuse Patient Records Regulation (42 CFR Part 2).<sup>xxii</sup> State laws may have additional patient protections (e.g., for patients with mental health conditions) or have additional data safeguarding requirements (e.g., for communicable diseases).<sup>xxiii</sup> States may specify consent standards. For example, Rhode Island Beacon Community requires that patients agree to allow exchange of their health care data by signing an authorization form (RI Gen Laws Section 5-37.7-4). Case law and legal precedence can also bring added complications. In Massachusetts, a 1985 case

dealing with paper records and the resulting uncertainty among legal experts on its application to electronic records was a key reason the Massachusetts eHealth Collaborative decided to adopt an opt-in consent model.<sup>xxiv</sup>

Policies such as consent models can significantly influence the time required to deliver value to participating entities. Rhode Island, for example, has a stringent opt-in consent policy that allows patients to specify which providers may access their data. This limits how HIE data can be used, such as for general population health reporting. Utah also allows patients to make an opt-in consent decision, and a 2011 Legislative Report noted that the “consent model poses a serious and significant delay in implementation, provider adoption and utilization thereby jeopardizing the potential to demonstrate value and generate a sustaining business case.”<sup>xxv</sup> Policies such as Rhode Island and Utah’s consent regulations make achieving critical mass challenging, but not insurmountable. Governing bodies can tackle these regulatory issues by understanding and collaboratively addressing risks early on.

These issues are just a few of the legal complexities a community must navigate to provide value securely, legally, and efficiently to its stakeholders. Exhibit 11 reflects the complexity of the needed legal analysis and corresponding policy generation.

**Protected health information (PHI)**, also referred to as personal health information, is information relating to the health or health care of an individual that can be used to identify the individual. It includes information such as diagnosis, medical history, test and laboratory results, insurance information, medical images, and demographic information.

*Exhibit 11: Federal and State Legal and Regulatory Context*

GOAL	FEDERAL AND STATE LAWS	CORE LEGAL AND POLICY TOPICS	KEY POLICIES AND AGREEMENTS
Establish a legal and policy framework that enables the electronic exchange of health information while protecting patients' privacy.	HIPAA and Federal Privacy and Security Laws	Security and Privacy Mechanisms	Consent Policy and Patient Consents
	State Healthcare & HIE Regulations		Security Policy
	HITECH		Authorization and Access Policy
	Consent & Liability Laws		Participation and Data Use Agreements
	State Contract Law	Participation, Oversight, and Accountability Mechanisms	Auditing and Accountability Policy
	Other State and Federal Laws		Insurance

A community-wide HIE effort can add value to its stakeholders by pooling resources to navigate legal and regulatory complexities. The ability to share legal expertise, rather than having to independently address these issues, can save participating entities both time and money. In addition, a collaboration of stakeholders can provide enough weight to successfully advocate for any needed changes in existing state law or development of new ones.

Creating a legal framework that complies with all Federal and state laws and regulations, protects the governing entity's directors and officers, and is acceptable to all participating entities is a challenge of significant magnitude. Nonetheless, it is a requirement. To develop the framework and supporting documentation, Beacon Communities' experience supports exploring the following process:

1. Engage the right expertise to navigate the complexity of the legal environment.
2. Develop the HIE legal framework and policies with the collaboration and engagement of all key stakeholders.
3. Provide initial and ongoing training for exchange users and participating entities.

### ***2.1 Engage the Right Expertise to Navigate the Complexity of the Legal Environment***

Specialized legal expertise is needed to establish a sound and effective legal infrastructure. The governing entity can designate an attorney who specializes in PHI stewardship to lead the development of that infrastructure and serve as the chief legal advisor to the governing board.

At the board level, a committee or workgroup consisting of legal counsel from each participating entity and chaired by the governing body's HIE legal advisor or chief privacy officer can improve the community's chances of developing a sound and effective legal framework. In this forum, each key stakeholder's HIE priorities and concerns can be voiced and addressed in a collaborative environment. Knowledge can be shared, proposed solutions vetted, and consensus achieved. This strategy often expedites the development process and reduces time required to create the legal infrastructure and supporting documentation. The legal workgroup's charge may include developing 1) the legal framework and supporting documents, such as legal agreements, policies, and standard language for use by participating entities in their own patient consent and authorization forms; 2) recommendations for oversight and accountability processes, including privacy and security standards, and mechanisms for validation and enforcement; 3) draft policies and procedures to support privacy and security standards; and 4) agreements governing data use and sharing among participating entities and end users. The framework and all supporting documentation will require approval by the governing board.

Legal advice is vital on other areas that may affect the governing entity, including contract law, state regulations governing health care and health information organizations, consumer protection laws, and financial reporting requirements. Establishing a liaison to state officials responsible for enforcing privacy and security laws and statutes is important, as well as creating a connection with consumer advocacy groups.

In addition to legal expertise, the governance board may consider appointing two additional roles once the exchange is operational: a privacy and security officer and a compliance officer. The compliance officer's role is to ensure compliance with all other laws and regulations outside of

privacy and security; conduct regular audits and monitoring activity; enforce corrective action plans; and work with local, state, and Federal officials to meet ongoing reporting requirements.

**2.2 Develop the HIE Legal Framework and Policies with the Collaboration and Engagement of all Key Stakeholders.**

A legal framework is necessary to guide policy creation and the downstream protocols, trainings, and guidelines that participating entities and their staff adopt. For example, the legal framework is the basis for creating privacy and security procedures. Those procedures are used to establish protocols for all security components (e.g., administrative, physical, and technical safeguards); recognize patients’ privacy rights and specify processes for fulfilling these responsibilities; instruct staff on what to do when something impairs the availability, integrity, or confidentiality of protected health information; specify a process and sanction policy for breach notification; and outline enforcement, such as the use of security logs to monitor access to the HIE systems.<sup>xxvi</sup> Ultimately, the goals of a comprehensive legal framework are to (1) define how protected health information will be exchanged accurately, safely, securely, and in compliance with all Federal and state laws and (2) set parameters for legal agreements informing and binding participating entities, end users, and patients to those policies as appropriate. Based on the experiences of Beacon Communities and other health information organizations, this section describes practical insights to:

- Research existing legal frameworks, policies, and resources.
- Establish security and privacy mechanisms.
- Establish participation, oversight, and accountability mechanisms.
- Obtain insurance to protect against legal liability.

See Exhibit 12 for some of the key attributes and components to be addressed by and included in HIE-related policies.

*Exhibit 12: Key Attributes and Components of Data, Policies, and Trainings<sup>xxvii</sup>*

Attribute	Description
<b>Availability</b>	<ul style="list-style-type: none"> <li>• The data must be available to the applications of all HIE users when needed.</li> </ul>
<b>Accessibility</b>	<ul style="list-style-type: none"> <li>• The agreement must ensure that the data is accessible, regardless of the application use.</li> </ul>
<b>Interoperability</b>	<ul style="list-style-type: none"> <li>• To the extent possible, the data must be both semantically and syntactically interoperable across systems.</li> </ul>
<b>Auditability</b>	<ul style="list-style-type: none"> <li>• There must be a trail of the data from its source to its destination.</li> </ul>
<b>Quality</b>	<ul style="list-style-type: none"> <li>• The data must be accurate and complete.</li> </ul>
<b>Security</b>	<ul style="list-style-type: none"> <li>• The data must be kept secure.</li> </ul>
<b>Confidentiality</b>	<ul style="list-style-type: none"> <li>• The data must be limited to appropriate users.</li> </ul>
Component	Description
<b>Standards</b>	<ul style="list-style-type: none"> <li>• All data definitions, structures, formats, and taxonomies must be in a documented agreement or included within a policy to facilitate interoperability.</li> </ul>

Component	Description
<b>Organization</b>	<ul style="list-style-type: none"> <li>The roles and responsibilities of each individual within the data governance program must be defined.</li> </ul>
<b>Processes</b>	<ul style="list-style-type: none"> <li>Processes must be defined around the creation, development, and management of data, including business rules and access and monitoring mechanisms.</li> </ul>
<b>Issue Management</b>	<ul style="list-style-type: none"> <li>There must be policies in place that guide data prioritization and remediation.</li> </ul>

### Crescent City Beacon Community: GNOHIE Foundational Elements: Policies & Procedures



GNOHIE considered the following elements to be the foundation for setting policies and procedures governing data exchange. These were approved by its governing body (called the Administrative Committee) and have been implemented to facilitate the operationalization of the GNOHIE.

#### *Patient Consent Model and Policy*

Based on three separate legal opinions regarding patient consent requirements under Louisiana law, GNOHIE adopted an opt-in model of patient consent in which patients must provide consent before any information can be shared among members of the GNOHIE. The GNOHIE Consent Form applies to the sharing of information among all GNOHIE participants and therefore does not need to be obtained separately by each participating organization.

The development of a patient consent model was a lengthy process that required the following:

- Development and adoption by GNOHIE members of a patient consent policy that addresses the community approach to consent, the process by which consent will be obtained and recorded, sensitive information categories, and how to handle patient requests for restrictions on the use or disclosure of protected health information.
- Development and adoption by GNOHIE members of a patient consent form. This includes utilizing a health literacy consultant to ensure the consent form is at a reading level appropriate for the patient population.
- Development of patient and provider staff reference and collateral materials regarding the patient consent process and ensuring that such materials are at an appropriate reading level.
- Translation of the consent form and associated patient reference materials into Spanish, Vietnamese, Portuguese, and Chinese.
- Development, testing, and implementation of a central method to record and update consent status within the GNOHIE, including training of provider staff members to utilize this system.
- Where possible, facilitating the development of functionalities in participating organization EMR systems to enable the entry of consent status in the EMR system, which links to update the consent status in GNOHIE in real time.

#### *Additional Policies and Procedures*

Several additional policies must be implemented before data can be shared through a health information exchange. The following additional GNOHIE operational policies were approved by the GNOHIE Administrative Committee in May-August 2012.

An **access control policy** must be put in place to set forth the requirements and parameters pertaining to the development of users with specific privileges and roles, instances in which consent can be overridden to “break the glass,” and account set-up.

A **breach notification policy** must be developed to clarify what constitutes a breach and a discovery of a breach. This policy must also clearly identify

- Responsibilities for reporting breaches, including requirements pertaining to employees, agents, and independent contractors of health information exchange members and their business associates.
- Method for reporting breaches.
- Methods and responsibility for notifying patients and GNOHIE participants of breaches.
- Notification of other entities such as the media and the Secretary of Health and Human Services.

A **data use, retention, and disclosure policy** must be developed to clarify to whom and the manner in which data may be used and disclosed, including use of data by GNOHIE participant business associates, the historical data maintained within the GNOHIE, data corrections, and restrictions on release of data.

A **grievance policy** must be developed to delineate participant and GNOHIE responsibilities in the event of a patient grievance.

A **sensitive data policy** must be implemented to address the blocking or suppression of the following categories of sensitive information:

- Psychotherapy notes.
- Mental health records for individuals younger than 18.
- Genetic testing information.
- Records from drug, alcohol, and substance abuse treatment facilities.

Source: [http://www.crescentcitybeacon.org/uploads/media\\_items/ccbc-3rd-annual-report.original.pdf](http://www.crescentcitybeacon.org/uploads/media_items/ccbc-3rd-annual-report.original.pdf)

#### *Research Existing Legal Frameworks, Policies, and Resources*

Communities should conduct research on HIE legal frameworks and policies already developed by other HIEs in their state and beyond, think tanks, government agencies, and other credible sources to understand how others have approached this task. This will also allow communities to anticipate the implications of local and state laws, e.g., state regulations governing the use of mental health-related data. Also, this will allow communities to avoid “reinventing the wheel”

and build on others' experience. For example, Beacon Communities have stated that developing data use agreements (DUAs) can take months, and possibly a full year. Using existing data use agreements or model language can save time and legal fees. Western New York Beacon Communities' data use agreement has been used a template for other communities. Communities can especially benefit if they draw on the experience of another community (1) in the same state or in a state with a similar regulatory environment (e.g., both are in opt-in consent states); (2) that has similar community-wide goals for implementing an HIE strategy (e.g., improve care coordination of congestive heart failure patients); and (3) is interested in implementing similar capabilities (e.g., developing a central data repository).

The Greater Tulsa Health Access Network Beacon Community stated that conducting a review of existing resources based on others communities' experiences or through research of materials (e.g., Federal resources, think tanks) added to its credibility at the onset and gave participating entities confidence that Tulsa had "done its homework." Being familiar with available resources and model agreements also allowed the lead convening entity and participating entities to make a case for best practices during negotiations. When it came down to drafting data agreements, each participating entity wanted its own stock provisions to be amended to any data agreement. The governing board and participating entities came to an agreement that amending DUAs with each entity's stock language was not conducive to the culture of collaboration they were seeking to foster. While it took months of negotiations, each party eventually agreed to have one set of participation agreements, which included standardized terms and conditions of participation (including DUAs) and policies and procedures (including those governing privacy and security).

For an example of DUA language, see Appendix C. Additionally, Appendix G includes a list of legal and regulatory resources that can serve as a starting point research.

### *Establish Security and Privacy Mechanisms*

Communities can develop privacy policies and procedures with regard to the following:<sup>xxviii</sup>

- **Opt-In/Opt-Out.** Some states have laws about whether patients must opt in to or opt out of HIE programs. The technical infrastructure must support those options, track patient preferences, and allow the patient to change preferences. In addition to complying with state regulation, the community must decide how to notify patients and how the electronic systems will track patients who have opted in or opted out, as appropriate. This includes having a flag in the electronic record, such as a data entry field that administrative support staff can use to enter information, and a rule within the EHR or HIE system that checks for the flag before sending data to recipient systems. In addition to general consents, some states or health care organizations require automatic exclusion of specific data types from exchange, including data related to behavioral health, sexually transmitted diseases, or HIV-related information. These exclusions can be difficult to manage in electronic systems because the system filters lack specificity, or the filters are not programmed for the needed data elements. In some cases, communities will have relevant patients opt out of HIE entirely rather than try to send an incomplete patient record.<sup>xxix</sup>

### Bangor Beacon Community: State Influence on Behavioral Health Data Sharing



For local providers, the state of Maine has advanced the cause of sharing important mental health-related data. Within the state, many important data elements can be exchanged without a patient's written consent, although patients may opt out of the exchange. Until recently, however, state law required that the HealthInfoNet health information exchange system exclude protected information, including all diagnosis and procedure codes associated with behavioral health services. This law limited the value of behavioral health providers to connect with the exchange. In 2011, the Maine state government addressed this barrier by amending state law, giving patients the choice to opt in to the exchange so that the primary care physician could receive behavioral health data through HealthInfoNet. Since then, HealthInfoNet has been actively campaigning to encourage consumers to sign their consent forms if they choose to do so.

Beacon Communities have experience in developing strategies to improve the opt-in rate among patients. For example, in 2010, Western New York Beacon Community (HEALTHeLINK) launched a month-long campaign to increase the opt-in rate by holding a public event where the CEOs of the region's leading hospital systems and health plans gathered to sign their own consent forms. At that point, about 90,000 individuals had signed their consent forms granting HEALTHeLINK access to their PHI for the purposes of data exchange.<sup>xxx</sup> By November, 2012, Western New York had successfully obtained 436,499 individual signed consent forms.

- **Collection, Use, and Disclosure Limitation.** Clear guidelines and transparent communication regarding the intended use of health information protects and informs patients, and builds the public's confidence in the HIE. The governance body will need to have a policy regarding whether a data repository will be maintained and, if so, who can access it, and what the data may and may not be used for. Allowable uses of the data varies widely across HIE organizations. Options considered often include analytics for population health management, comparative analytics across providers, and selling de-identified health data to commercial or academic institutions for research purposes. The Southeast Minnesota Beacon Community, for example, cordons off data within the clinical data repository so that only the contributing organization can see its data. Once the data use and disclosure policies are established, these should be communicated to patients using patient-friendly language (e.g., easy to read, minimal jargon) and in multiple formats (such as a pamphlet, poster in the clinic, and webpage).

## Western New York Beacon Community: Understand Local Authentication Requirements



In Western New York, some hospitals required two-factor identification and, as a result, authentication became one of the primary challenges for HEALTHeLINK, the regional HIE. Authentication is, simply, a way for an organization to confirm identification before allowing access to an electronic system. The traditional method for authentication is a password associated with a user name. Two-factor authentication means that a user must also present some other proof, such as a biometric fingerprint or token.

In Western New York, several hospitals had a local policy that required two-factor authentication for anyone accessing data in the electronic health system. HEALTHeLINK, as a result, had to require two-factor authentication for anyone accessing the patient data. While more secure, this also became a burden for users who had to provide both factors of identification each time they wanted to view a patient's information. HEALTHeLINK ultimately transitioned to 12-hour authentication, thus mitigating the need for users to re-enter their credentials during the newly extended authentication time period.

- **Authentication.** Staff and partner organizations may need direct access to the HIE system, and the organization will need a policy determining who will get access and to which system functions. It must also decide how it will authenticate users – in other words, how it will validate that people are who they say they are (e.g., through a login and password or other credentials). This process may occur on paper, electronically, or across both formats. In addition to a process for allowing appropriate users access to the system, the organization should have an auditing process to identify and follow-up on inappropriate requests (e.g., a user submits a request for which he or she does not have permissions) and any other use that is not in compliance with established policies and procedures. As communities add new partners, they should confirm the local authentication requirements as part of the overall technology and policy scan and evaluate the benefits of one- and two-factor authentication and how to balance security with convenience for users.

### *Establish Participation, Oversight, and Accountability Mechanisms*

To complement access and authentication policies, organizations also create policies defining how they will share data with other entities and patients directly. Data sharing is the crux of a HIE system and effective policy creation facilitates orderly information exchange. In particular, enforcement is a critical area to address during early policy creation so that participating organizations are prepared in the event of a breach of sensitive information. Subjects that organizations may cover as part of this topic include:

- **Data Use Agreements.** A DUA is a core component of the legal framework. Broadly, the DUA defines the data sharing roles, relationships, and responsibilities between and among the participating entities. It specifies what data will be shared, who can access the data and how, what the data can be used for, and how the organization will handle data

breaches and violations of data use policy. It preserves compliance with HIPAA, HITECH, and state laws.<sup>xxxii</sup> DUAs may already be in place between participating organizations that can be used for broader data sharing. Even in this case, additional amendments will likely be needed to cover data sharing within HIE. If an amendment is required, the legal workgroup creates it, the governance body reviews it and accepts changes in language to the DUA, and then signatures are obtained from all participating entities.

- **Consumer/Patient Access.** The governance body must also address how it will handle patient information requests. This will be particularly pressing if there is no patient portal for the patient to directly access information and patient information request have to be handled individually. Once the policy is developed, a strategy to inform patients of the process for obtaining information will be helpful. A clear process will be needed for staff fulfilling the requests that address individual responsibilities, expectations for a timely response, and the format by which they will send records to patients. For the Western New York Beacon Community, New York State has a series of policies instructing HIOs on how to address patient access.

In addition to traditional print and mail, fax, and CD chart requests, personal health records (PHR) or patient portals can provide real-time or near-real-time access for patients to their own health records. Stakeholders may have to decide, within the scope and functionality of the electronic system, what information the community will make available electronically to patients. For example stakeholders will need to determine whether the system should:

- include the entire medical record or instead focuses on key data elements, such a medications, orders, results, appointments, allergies, immunizations, vitals, and diagnoses, and
- exclude other data elements, such as physician notes or free-text fields.

In addition, some organizations choose to include a delay before some information is visible. For example, a negative lab result may not appear immediately to give the physician time to call the patient and discuss the findings. A second important issue is disclosure of medical information for minors and to what extent parents or guardians can access a minor's PHR. This consideration, for example, influenced the Southeast Minnesota Beacon Community's Asthma Management Toolkit, which included a school-based portal for students. The toolkit includes written policies and processes for parental consent.<sup>xxxiii</sup> Finally, along with deciding what information to share with patients, it is important to provide ample reference ranges and help guides to explain what the data means and how to use the tools.

- **Corrections.** The governance body should establish policies and corresponding procedures for addressing patient requests for corrections to their health record or disputes regarding the accuracy of medical record information, including points of contact.<sup>xxxiii</sup> This issue is often included in the DUA because the source of the error may be one of the participating organizations or could originate within the HIE system directly.
- **Safeguards and Accountability.** The governance body can establish how to monitor for breaches and where responsibility lies for patient confidentiality and compliance with HIPAA and state law. Role-based access, including determining the criteria for what

different groups of users have access to see in the system, is an important step. Criteria for role-based access can include clinical licensure, facility, and completion of training, among others. Auditing functionality enables the HIO to monitor for breaches. Auditing checks include: tracking who has accessed the HIE system, what they have viewed, if they requested emergency access to view the chart, and the date and timestamp. See Exhibit 13 for auditable types of information and characteristics of the audit reports.

In addition to ensuring the system can provide audit reports, the governing body will decide on the frequency of reporting, who will run and review the reports, and how results will be presented back to the governing body, and to the community.

*Exhibit 13: Example Auditing and Logging Checklist from the Markle Foundation*

Questions	Yes	No	N/A
1. The system is required to log users' system log in and log off with date and time, or, if the system cannot record log in and log off activity, it may rely on an external security system's access control logging function to record access.			
2. The system must have the ability to log, read, create, update, delete, forward, and print access initiated by individuals and processes for systems containing confidential and restricted data. For data warehouses, data marts, and operational data stores, the system must have the ability to log queries or, alternatively, the tables read must be logged. Row-level logging must be available on demand.			
3. All audit records must be identified by a unique record key or number, and include: <ul style="list-style-type: none"> <li>• User identifier or name of user.</li> <li>• Time and date.</li> <li>• Device identifier (when used to access).</li> <li>• Source (i.e., subsystem or system of origin of the event [access request]).</li> <li>• Type of action (e.g., read, write, update, delete, or copy) or access for diagnostic purposes.</li> </ul>			
4. Unsuccessful login attempts and access violations within the system must be logged.			
5. Security administrative functions must be logged.			
6. System administrative functions must be logged.			
7. Audit records must be protected against unauthorized access, modifications, and deletion.			
8. Audit records must be readily available for 90 days and archived for a minimum of two years, or up to the six years used for the archiving of HIPAA disclosures.			
9. Security administrators and auditors can request or generate reports that may consist of any or all of the audit record elements for any or all types of actions.			

Source: Adapted from the Markle Foundation, P7: Auditing access to and use of a health information exchange, Markle Common Framework for Private and Secure Health Information Exchange. Available at <http://www.markle.org/health/markle-common-framework/connecting-professionals/p7>. Accessed June 9, 2013.

### *Obtain Insurance to Protect Against Legal Liability*

HIE organizations, their governing boards, and participating entities have exposure to risk for litigation as a result of data privacy and security breaches. They are also vulnerable to penalty fines by regulatory agencies for breaches and non-compliance with any number of rules. Some states, financial contributors, and organizations participating in the HIE will require insurance policies as part of establishing health information exchange capabilities. Relevant insurance policies can include:

- Liability insurance. General liability insurance protects the organization from lawsuits within the scope of the policy.
- Directors and officers (D&O) insurance. These policies provide reimbursement to an organization's directors and officers or to the organization directly to reimburse expenses from a legal action related to alleged wrongful acts by its leadership.
- Errors and omission (E&O) insurance. E&O policies cover a health care organization in the event that a client or customer holds the organization responsible for services that have been provided, that it failed to provide, or that did not have the expected or promised results. It is a type of professional liability or malpractice insurance that covers the policyholder for legitimate errors or omissions and those that the client or customer perceive as legitimate.
- Data privacy insurance. Some insurers offer data privacy protection to health care organizations, and organizations such as HIOs that deal with PHI. These policies typically cover legal costs and fines assessed by a regulatory body for data privacy breaches.

It is important that an attorney review policies to ensure they provide adequate coverage against potential exposure. In buying insurance, a consideration will be whether coverage will be limited to the HIO or extend to others such as subcontractors and business associates.

### *2.3 Provide Initial and Ongoing Training for Exchange Users and Participating Entities*

Beacon Communities and entities participating in data exchange agree that the rules for handling PHI can be complex and, therefore, education and training for all users, delegated entities, or vendors that will handle PHI is a best practice. In addition to state and Federal rules and regulations, trainings can also encompass community-wide and entity-specific policies and procedures. Privacy and security trainings both at the inception of HIE and annually thereafter are needed for exchange users and participating entities. Specific training needs may vary based on data usage. Communities can consider the following questions when deciding on the amount and type of trainings needed:

- Are user roles clearly defined?
- Does our staff need additional training to make HIE work?
- Does our staff have the right skills (capacity) to implement and maintain HIE functionalities and compliance?

Successful communities remain vigilant with their training programs, requiring annual retraining of all users and adapting the training to reflect changes in the organization's policies and

procedures, as well as HIE technological advancements. It is vital to monitor workflows and related policies to ensure staff members have sufficient and up-to-date training and support. For example, the Southeast Minnesota Beacon Community formed HIE Transition to Practice (HIETOP) in August 2012 to help practices adopt HIE. Led by physician and user champions from all participating entities, HIETOP subgroups looked at documentation including the content of Continuity of Care documents (CCDs), use case-based workflows, training documents, help desk workflows, an outcome measurement document, and user survey results. These subgroups identified ways to optimize both workflows and technology to encourage better adoption by staff and helped roll out these changes to the practices.

#### Key Considerations for a Governing Board

- Will stakeholders commit the resources needed to establish a strong and effective legal framework?
- Will stakeholders encourage their legal representatives to find solutions rather than problems?
- How will the governance body and participating organizations enforce policies that protect the confidentiality of patient information?
- Will stakeholders execute the agreements and change their workflow process and documentation requirements to enable full use of the HIE?
- Who will provide training for HIE staff and participating entities?

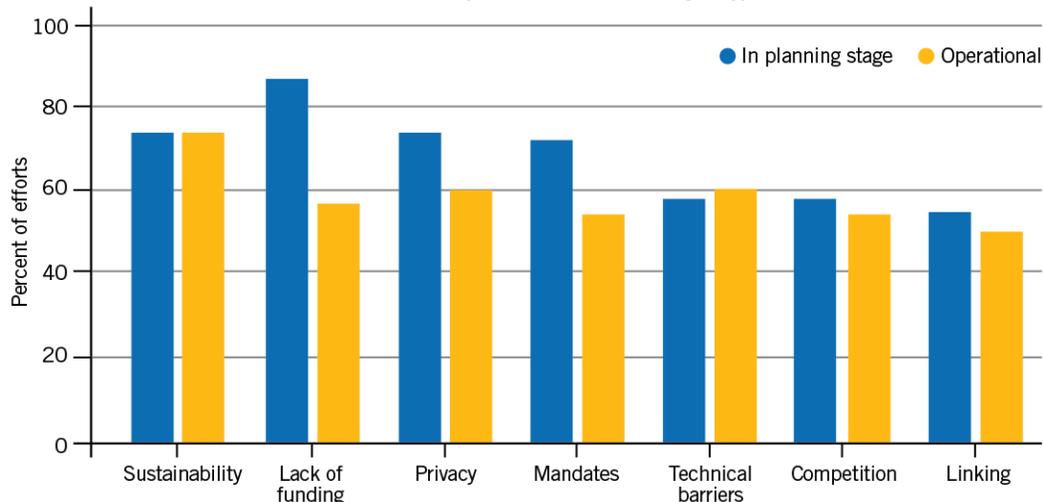
### Strategic Objective 3: Identify Funding Sources and Define the Financing Strategy

Numerous surveys of entities that have established HIE indicate that sustainability is both difficult to achieve and important to plan for throughout the implementation. These entities recommend integrating sustainability modeling into HIE planning, implementation, and maintenance phases because substantial time is required to establish a financial value proposition.<sup>xxxiv</sup> Generally, sustainability challenges fall into three areas:

- Misalignment of financial incentives among key stakeholders.
- Misalignment of HIE costs versus revenue.
- Overreliance on limited (or single) service offerings or funding sources.

Establishing a financing strategy is particularly challenging in today's environment, where HIE organizations are still in the midst of developing sound long-term sustainability models, and American Recovery and Reinvestment Act (ARRA)-related Federal funding for HIE efforts is ending. A 2013 survey of 173 participants in proposed and live health information exchange efforts identified sustainability and funding as the greatest barriers to the development of health information exchange efforts (see Exhibit 14).<sup>xxxv</sup>

**Exhibit 14: Barriers to Health Information Exchange Identified by Planned and Operational Health Information Exchange Efforts**



Source: Adler-Milstein, J., D.W. Bates, A.K. Jha. (2013). Operational health information exchanges show substantial growth, but long-term funding remains a concern. *Health Affairs*. 8:1486-1492.

Whether developing sustainability strategies around existing HIE platforms, or supporting the launch of new exchange solutions, Beacon Communities explored a range of revenue generation and financing options as part of their program efforts. This Strategic Objective provides an overview of the startup and operational costs that are typically incurred when establishing HIE services and identifies initial and ongoing funding sources. It also reviews the process for developing a financial model for long-term sustainability in collaboration with regional stakeholders. This section describes key considerations for each of these activities and is organized as follows:

1. Identifying startup and ongoing operational costs.
2. Developing a financing strategy for startup and ongoing operations.

### 3.1 Identify Startup and Ongoing Operational Costs

The costs associated with developing exchange solutions can be broadly grouped into start-up costs and ongoing operational costs. These costs vary depending on the corporate structure established by the governing body and the services it seeks to establish. For example, establishing a central data repository-based exchange among multiple entities will require a different level of investment and infrastructure development than Direct-based secure messaging between two entities.

Start-up costs encompass components required to initiate the planning and design of HIE. Typical startup costs can be grouped into two categories: <sup>xxxvi</sup>

**Capital investments** related to infrastructure, typically technology purchases.

**Administrative costs**, which can include human resources and staffing costs; HIE design services, including technical architecture, business design (e.g., business planning, financial modeling) and

operational planning; marketing and communications; legal services for establishing a framework for data sharing; and privacy and security services.

Maryland CRISP estimates the start-up costs of developing its HIE: over the course of four years, it expended \$8.5 million on capital investments, including \$8 million on technology and \$500,000 on capital equipment. In addition, it reports spending approximately \$8 million on administrative costs, including \$1.5 million on direct staffing and consultants and \$6.5 million on contracted labor.

Ongoing operation and maintenance costs vary based on the model for HIE, number of data types and sources, how easily data sources exchange information (e.g., ability to translate data into standardized formats), the legal framework, and the number and types of participating entities involved in exchanging data. Typical operational costs may include:<sup>xxxvii</sup>

- Hosting service and data service costs.
- Ongoing administrative costs, including leases, staff, and marketing.
- Other operational costs, including licensing and maintenance fees; hardware and software upgrades for improved or additional functionality; and maintenance fees, insurance, and legal fees.

The San Diego Beacon Community estimates its ongoing costs as approximately \$1.8 million per year, including ongoing human resources support at 50 percent of operating expenses and other administrative costs estimated at 5 percent to 10 percent of operating expenses. The Tulsa Beacon Community estimates its total cost over the course of approximately three years to be \$15 million with 50 percent going to labor and other expenses; 45 percent going to IT and related contracts; and 5 percent to administrative costs (such as finance, accounting, and HR).

### **3.2 Develop Financing Strategy for Startup and Ongoing Operations**

The financing strategy should specify start-up and ongoing operational costs and how the community will pay for them, including funding streams, when the organization is expected to capture each funding stream, and the income trajectory. Typically, this information is displayed in a pro forma financial statement, which is part of the business plan. The business plan will also include a financing discussion that includes a capture strategy for funds.

#### **Identify Funding Sources**

A 2010 HIMSS survey of HIOs reported that “the larger portion (65 percent–70 percent) of funds needed for HIE implementation and operation are coming from state and Federal grant programs.”<sup>xxxviii</sup> However, given that the opportunities for Federal funding are growing smaller as HITECH investments sunset, the governing body of the HIE organization should consider several options for initial funding. Potential funding sources include all stakeholders who are current HIE participants or whose goals and vision align with those of the HIE community. These funding sources include:

- Federal funds for activities that enable EHR adoption and HIE, such as CMS Medicaid Transformation Grants and Medicaid EHR Incentive Program Funds.

- Public grants from states, nonprofits, and other entities seeking to fund HIE efforts.
- Hospitals.
- Payers.
- Physician practices.
- Philanthropic sources, such as private or corporate foundations.
- Employers.
- State funds, for example Vermont’s state assessment on claims.

Sources of start-up funding may also include private investment, loans, government, foundation, and corporate grants. Potential private investors and lenders, such as large hospitals or health systems, health IT vendors, venture capitalists, and banks could be early beneficiaries of HIE capabilities.

### *Establish Ongoing Revenue Generation Strategies*

Entities seeking to establish or expand exchange capabilities can use a variety of methods to generate revenue. One successful method involves selecting the mix of services and associated pricing that works best for stakeholders given their goals, partners, community needs, and desired level of revenue generation. This allows the governance body to model the various scenarios under consideration and project potential revenue, risks, and benefits before selecting the optimal approach. The Western New York Beacon Community, for example, conducted ROI studies at both the community level and for each participating entity. Meanwhile, the Crescent City Beacon Community is trying to demonstrate the value of the exchange to payers through improved care coordination and reduction in avoidable hospitalizations and readmissions by calculating this value in the form of per member per month (PMPM) savings. Crescent City has had to explore a variety of ways to credibly establish these data points given incomplete information about costs available for patients’ use of services and difficulties isolating the effect of data exchange on outcomes over a relatively short period of time. However, Crescent City has set up the necessary data capturing, gathering, and analysis infrastructure to be able to measure this value in the future.

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### Potential HIE Services

- E-prescribing
  - Hospital admission, discharge transfer alerting
  - Secure messaging
  - Lab and radiology results delivery
  - Image sharing (i.e., x-rays, MRI, other)
  - Claims processing
  - Prior authorization requests
  - Eligibility verification
- 

Strategies for generating revenue include:

- **Grants.** Grant opportunities may be available at the state-level and from private institutions interested in advancing exchange. It is important to note that much of the direct Federal funding for exchange establishment and development has already been awarded.
- **Periodic or Service-Based Subscription Fees.** Entities may consider using subscription fees applied periodically (e.g., monthly, annually, other) or for use for a certain type of

service (e.g., clinical services, such as e-prescribing or secure messaging or administrative services, such as claims processing). Some entities tie subscription fees to fixed variables; for example, San Diego hospitals have negotiated usage fees based on the number of hospital beds. Subscription-based fees are considered a relatively stable revenue stream as users enter into contracts with established set fees.<sup>xxxix</sup>

The Tulsa Beacon Community collects revenue using adjusted patient days as the basis on which to collect fees.

- **Transaction-Based Fees.** These fees are usually applied to services, such as secure messaging or accessing lab results, claims, or eligibility transactions. Transaction-based fees can be variable, as usage can vary depending on user needs. A transaction-based fee approach may require more oversight and may not be attractive to large organizations that require access to services at high volumes.<sup>xl</sup>
- **Utility Model.** The utility model treats HIE as a public utility and shared benefit. Accordingly, states are considering some form of tax to fund HIE activities.<sup>xli</sup> This revenue generation method is gaining traction among a range of communities. Vermont established a health IT fund in the state treasury to fund HIE development among other health IT-related efforts. The funding comes from a fee assessed on commercial payer claims.<sup>xlii</sup> Three payers fund the Western New York Beacon Community HIE services on behalf of the community and charge back through premiums or rates. These payers make up 70% of the commercial market in Western New York. Patients and providers who are not part of their networks benefit from Western New York HIE services without paying for them, as are other payers in the community. Western New York is attempting to address this issue of “free riders” by exploring options for other payers in the community to also share the financial burden and by trying to identify other sources of revenue such as using current and expanded service offerings to sell within and outside of the Western New York region.
- **Shared Revenue Model.** This model allows a third-party vendor (e.g., e-prescribing service) to offer services and have the HIE governing body and potentially the HIE partners share a percentage of the generated revenue. This model runs the risk of requiring more complex data use agreements.<sup>xliii</sup>

Financing strategies may evolve over time and start with one or two potential revenue streams that are easy to implement and diversify in both complexity and scope, as HIE gains traction within the community and funding for ongoing operations and maintenance becomes more stable.

### *Financial Measures and Sustainability*

Financial measures related to sustainability are helpful for keeping the HIE governing body aware of the financial viability of its efforts and can be used to inform future decision making. Discussed further under Strategic Objective 5, many Beacon Communities are collecting or plan to collect measures that describe ROI, value (e.g., elimination of duplicative services or waste), and financial health (e.g., days of cash on hand, diversification of funding sources). ROI and value metrics in particular can be powerful when constructed at the stakeholder level to show how different employers, providers, payers, and other stakeholders benefit from exchange services.

While valuable, the relationship between HIE and clinical quality and efficiency improvement can be difficult to measure. The Indiana Beacon Community and researchers at Brandeis University are developing an approach for measuring the correlation between sharing radiology results among clinicians in different health care settings and the reduction in redundant diagnostic orders. Communities will benefit from efforts to develop better measures to judge the value of data exchange; as such, measures can advance the business case for improved information sharing and help communities obtain the necessary buy-in for financing exchange efforts.

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### **Data Exchange to Support Payment Reform Efforts**

Health information exchange organizations are creating partnerships with local payers and large health systems to establish the business case for data exchange – specifically, that it is vital to share claims and quality information to support measurement and reporting required for payment reform. For example, both the Colorado Beacon Consortium and the Greater Cincinnati Beacon Collaboration are working with local payers to integrate claims data along with clinical data into their HIE efforts. Colorado’s local payer partner plans to use this data to identify best practices for managing panels of patients across its network.

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#### **Key Considerations for a Governing Board**

- What startup funding sources should communities target for planning, design, and implementation of HIE?
- How do the cost and revenue model results inform selection of HIE services and associated financing and pricing strategies?
- What HIE financing strategies should the community use for planned services?
- What pricing strategy should the community use for these services?
- How can the community proactively address financial challenges throughout the planning, design, and implementation process?

#### Strategic Objective 4: Define Available Technology Paths to Facilitate Data Sharing

With the growth of HIE capabilities across the country, communities can increasingly build upon existing systems or services to enhance their own exchange capacity. The Beacon Communities frequently relied on available technologies to expand exchange capabilities, such as the prevalent use of the Direct protocol for secure, provider-to-provider email. Using available systems, services, and standards reduces unnecessary duplication and can reduce the costs associated with developing or acquiring new technology. This assessment informs strategic and tactical technical decision making regarding the future of an organization's health information exchange capabilities. The Beacon Communities found it important to balance broad engagement and communication with identifying a smaller subset of stakeholders to assess, recommend, and evaluate technology solutions. Although engagement throughout the selection process can improve adoption later in the project, a smaller set of empowered stakeholders can help the organization make important decisions in a timely manner.

The following sections cover approaches toward performing the assessment and the importance of including stakeholders in the evaluation process:

1. Building on and connecting existing platforms for exchange.
2. Evaluating technology solutions as a community.

##### *4.1 Building On and Connecting Existing Platforms for Exchange*

An important starting point for any effort to expand a community's HIE capabilities is establishing an understanding of the existing exchange landscape. The HIE technology landscape includes all the systems, services, and functionality within or accessible by participating organizations. In addition, stakeholders should develop a broad understanding of EHR adoption by community members and the extent to which organizations have the ability to exchange health information. They should also assess what works well and what needs to be further enhanced or developed. One Beacon Community, for example, emphasized the importance of performing a thorough environmental scan due to the challenges it experienced as a result of not fully understanding its partners' capabilities. Eager to achieve interoperability, the Community opted to work with the region's existing EHR and health information exchange systems. The systems had significant limitations, which could have been uncovered through a thorough and systematic assessment, and ultimately delayed the development of the community's exchange capabilities.

A comprehensive technology scan includes several types of actors and looks beyond familiar stakeholder organizations to also consider other communities and HIOs – even those from other states. This allows stakeholders to make informed decisions about the primary audience and available technologies for potential reuse. Exhibit 15 describes the actors for an environmental scan and questions that each actor may need to answer to ensure a complete scan of the technology landscape. The questions look at both current-state infrastructure and upcoming technology initiatives.

*Exhibit 15: Elements of a Comprehensive Environment Scan*

Actors	Characteristics
<p><b>Overall</b></p>	<ul style="list-style-type: none"> <li>• Broadband Internet access.</li> </ul>
<p><b>Hospitals and Provider Organizations</b></p> <p><i>Include physician-based, non-physician-based (e.g., physical therapy and community care management), adult and pediatric hospitals, urgent care facilities, long-term care hospitals, and other specialty groups, such as labs and pharmacies. Can also include Federal entities (e.g., the Department of Veterans Affairs, the Centers for Disease Control).</i></p>	<ul style="list-style-type: none"> <li>• EHR adoption (complete and/or by module).</li> <li>• EHR user satisfaction.</li> <li>• EHR and specialty system vendors.</li> <li>• Functionality (e.g., registration/billing, clinical documentation, computerized physician order entry ([CPOE])).</li> <li>• Personal health record (PHR) access and adoption.</li> <li>• Meaningful use compliance (including e-prescribing, lab interfaces).</li> <li>• Disease and immunization registry participation.</li> <li>• Quality measurement capability.</li> <li>• HIE capability (including exchange partners within and external to the health system, transaction types, and standards).</li> <li>• General demographics (e.g., staff size, patient volume, number of records, uptime, time live).</li> <li>• Upcoming launches (e.g., new functionality, new systems, rollout to new facilities, upgrades).</li> <li>• Known limitations and functionality requests.</li> <li>• Acquisition strategy.</li> </ul>
<p><b>HIOs and State HIE Organizations</b></p> <p><i>Designated organizations that oversee and govern the exchange of health-related information among health care organizations according to nationally recognized standards.</i></p>	<ul style="list-style-type: none"> <li>• Services.</li> <li>• Transaction types.</li> <li>• Trading partners.</li> <li>• Exchange structure (centralized, federated, or hybrid).</li> <li>• Consent model.</li> <li>• Transport support (point to point versus web services).</li> <li>• Service provisioning model (e.g., SaaS, ASP).</li> <li>• System model (single solution, best of breed, or EHR-based).</li> <li>• Messaging and terminology standards (e.g., HL7 version, C-CDA).</li> <li>• Upcoming launches.</li> <li>• Known limitations and functionality requests.</li> </ul>

Actors	Characteristics
<p><b>Payers</b></p> <p><i>Claims systems used by insurance companies can also participate in HIE initiatives. May include government organizations such as the Center for Medicare &amp; Medicaid Services (CMS) or Social Security Administration (SSA).</i></p>	<ul style="list-style-type: none"> <li>• Claims system vendors.</li> <li>• Functionality and data collected (e.g., claims, quality measures).</li> <li>• Quality measurement and analytics capability, data required for HEDIS reporting.</li> <li>• HIE capability (including trading partners, transactions, standards).</li> <li>• General demographics (e.g., organization size, claims volume, records, uptime, time live).</li> <li>• Major health system partners.</li> <li>• Upcoming launches.</li> <li>• Known limitations and functionality requests.</li> </ul>
<p><b>Regulatory Entities</b></p> <p><i>Exist at the state level, such as the Virginia Department of Health's Office of Health IT, and Federal (e.g., CMS or ONC). The State HIE program within ONC specifically addresses HIE.</i></p>	<ul style="list-style-type: none"> <li>• Major initiatives.</li> <li>• HIE grant programs and/or services.</li> <li>• Exchange constraints and guidelines (e.g., patient consent and sensitive data laws).</li> <li>• Available tools and resources (if applicable).</li> </ul>

Obtaining intelligence about the technology environment can be challenging as competitive business drivers may compound the challenge of collecting information for a comprehensive technology scan. Beacon Communities noted that some participating entities hesitated to share systems information because it would become available to competing health care organizations. Governance bodies may need to determine what information is required, what can remain proprietary to the organization, or what the organization can present anonymously. Even with complete transparency, the diverse number of stakeholders, systems, functionality, and standards make it challenging to fully capture the complete technology environment. A dynamic environment, with organizations rolling out new tools or switching to a new electronic health record can also present challenges to developing a timely understanding of stakeholders' capabilities.

**Standards**

The technology scan can include an assessment of messaging, transport, and documentation standards adoption. The number of standards and the technical or clinical complexity, respectively, can make it difficult to fully capture the current environment, but this information helps stakeholders decide on standards requirements for new and enhanced capabilities.

Even with strong standards adoption, Beacon Communities found that EHR certification does not necessarily mean that a system can easily exchange data, and users should carefully assess system exchange or interoperability capabilities. One Beacon Community, for example, noted that its major participating organizations used the same electronic health record but still struggled with exchanging CCD-formatted health information because they used different EHR versions and had facility-specific configurations. The environmental scan can help stakeholders prepare for the level of work needed to enhance exchange capabilities. (For additional information on standards, see the resources listed in Appendix E: List of Acronyms and Key Definitions)

- **Messaging (or transport) standards** support easy and efficient information exchange. Common structural standards include web services (e.g., simple object access protocol [SOAP]), secure transport and encryption protocols such as SMTP & S/MIME (i.e., Direct), and support for the NwHIN or eHealth exchange.
- **Terminology (or semantic) standards** vary across data types and level of adoption. Common examples include the following:

Data Type	Standard
Diagnoses	<ul style="list-style-type: none"> <li>• Internal Classification of Diseases (ICD) (e.g., ICD-9-CM, ICD-10).</li> <li>• Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT).</li> </ul>
Procedures	<ul style="list-style-type: none"> <li>• Current Procedural Terminology (CPT).</li> </ul>
Labs	<ul style="list-style-type: none"> <li>• Logical Observation Identifiers Names and Codes (LOINC).</li> <li>• CPT.</li> </ul>
Medications	<ul style="list-style-type: none"> <li>• RxNorm.</li> <li>• National Drug File (NDF).</li> </ul>

- **Document (or format) standards** ensure that organizations exchange relevant and readable data. Common document standards include HL7, the CCD for complete patient summaries, and Digital Imaging and Communications in Medicine (DICOM) for radiology images.

The Beacon Communities have used external forums to attempt to resolve challenging standard-related situations. The Communities, for example, collaborated to form the Beacon EHR Vendor Affinity Group, a workgroup with Beacon Community and vendor participation and focused on improving CCD-based exchanged. Starting from the most widely deployed content standard (HITSP C83), the Affinity Group worked towards reaching a consensus on 66 priority data elements required to satisfy impactful data exchange in support of the Beacon Community goals.

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(HITSP C83), the Affinity Group worked towards reaching a consensus on 66 priority data elements required to satisfy impactful data exchange in support of the Beacon Community goals.

### *HIE Systems and Services*

An analysis of HIOs and HIE capabilities can include both the systems and services. An HIO, for example, may use a single vendor solution for most components that support exchanging health information or combine a mix of best-of-breed technologies. Some EHR vendors also offer the ability to exchange health information, either solely with organizations using that EHR or across to other electronic systems. The services these systems offer fall into these general categories:

- **Core Services.** Examples include the Master Patient Index (MPI), Record Locator Service (RLS), authorization and authentication, patient consent management, auditing, provider directories, business continuity, data management, and message validation and translation.
- **Functionality.** Examples include provider-to-provider secure messaging including Direct messaging, e-prescribing, and lab or imaging result interfaces.
- **Reporting.** The ability to run analytics or business intelligence reports.
- **Decision Support.** The ability to trigger alerts to downstream users.

Data management is a particularly important characteristic. HIE systems may include centralized data repositories, federated structures with all patient data remaining on local systems, or a hybrid model that combines elements of both.

### *Available Systems and Services Assessment*

As HIE capabilities expand nationally, health care organizations find more opportunities to link to existing exchanges and share services.

### The Keystone Beacon Community Developed Key HIE Transform to Extract Relevant Data for Skilled Nursing Facility and Home Health Care Patients from Existing Systems

**KEYSTONE**  
BEACON COMMUNITY

A Keystone Beacon Community goal was to facilitate richer information sharing among nursing homes and home health agencies. These groups were challenging because they either did not have a health record or did not have one that was easily connected to a standard exchange. However, skilled nursing facilities are required to submit standardized electronic patient assessment information to CMS, known as the minimum data set (MDS), while home health agencies must submit information called the Outcome and Assessment Information Set (OASIS). The Keystone Beacon Community technology team developed a new tool called KeyHIE Transform that automatically extracted MDS and OASIS information from the records of patients who have provided consent for their data to be shared. The information then can be transformed into a standard CCD-like format able to be consumed by health information exchange systems in the same way as electronic health records sent by hospitals and primary care providers.

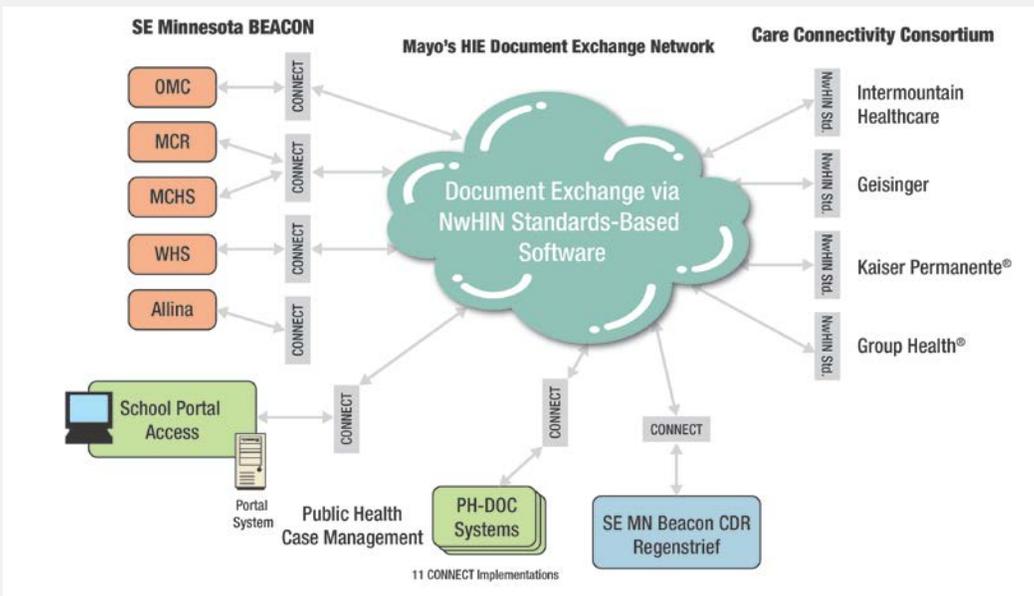
Although the availability of services varies across states, the following are common starting places for organizations interested in sharing resources or taking advantage of existing technology and services rather than creating something new:<sup>xliv</sup>

- **Direct-enabled secure messaging.** Direct is an open-source solution for secure, provider-to-provider messaging.
- **ADT-based alerts.** Automated alerts delivered to a primary care physician or care coordinator based on a patient's recent ED visit or admission, discharge, or transfer (ADT) are used to improve communication and care transitions. State health information exchange organizations across the country and their vendors have already implemented or will be implementing this functionality. In addition, some established HIOs have discussed expanding existing use of ADT-based alerts to other communities or health care systems.
- **Health Information Service Provider (HISP) services support.** HISPs support secure-transport via Direct by providing Direct addresses, publishing and managing digital certificates, encrypting and routing Direct messages, and storing messages if needed. A third party (e.g., payer, vendor) or the sender/receiver can provide these services.
- **eHealth Exchange.** Formerly called the Nationwide Health Information Exchange (NwHIN or NHIN), the eHealth Exchange supports a query-based exchange model. It has an onboarding process for organizations looking to use the specification and communicate with the larger network.

## How the Southeast Minnesota Beacon Community Created HIE Capabilities



Starting in 2011, the Southeast Minnesota Beacon Community worked with its participating partner organizations including the Mayo Clinic in Rochester, Mayo Clinic Health System, Olmsted Medical Center, Winona Health, and Allina Hospital to choose a technology strategy for electronic exchange. It decided to adopt a model endorsed by the Health Information Network Exchange (NwHIN). The partners decided that the peer-to-peer exchange model endorsed by the NwHIN would be a more effective approach to meet meaningful use requirements than a previously proposed hub-and-spoke model. The peer-to-peer model, however, would be viable only to a small group of exchange partners. As a result, the member organizations settled on a shared services model for scaling the peer-to-peer HIE to a larger cross-section of stakeholders. Additionally, the member organizations decided that while the greater community would design the overall technology strategy, the individual organizations would retain autonomy to implement the necessary gateways and other technologies to comply with the strategy. By April 2011, Southeast Minnesota had equipped each participating partner organization with the strategic framework needed to further develop their individual connectivity strategy using NwHIN protocols. Partners then worked with their respective EMR vendors to generate CCDs.



- **Blue Button.** Some HIE strategies put the patient or consumer at the center of managing personal health information, such as through personal health record portals. Blue Button is an example of a freely available standard for patient download of personal health information and a means of supporting consumer-mediated transport.
- **Analytics tools and infrastructure.** Communities frequently pool resources to support analytics. The technology assessment can evaluate whether any organizations, such as public health, a university, or a large integrated health care delivery system, have the ability to coordinate analytics for the community.
- **E-prescribing systems.** EHR vendors and vendors that specialize in e-prescribing can support this service.
- **Patient portals and provider portals.** The community can acquire secure portals for patients and staff as services from third parties.
- **Immunization registries.** The community may contribute to existing immunization registries.

For additional information, see the resources listed Appendix F: HIE Capability, Architecture and Interoperability Standards—Resource List.

#### 4.2 Evaluate Technical Solutions as a Community

Making technology-related decisions requires balance between comprehensive stakeholder input and a smaller, more nimble decision-making body. While all participating entities may be invited to provide input into the overall technology strategy, the Beacon Communities found that the final decision-making on technical strategy and vendor evaluation was best delegated to a smaller group of individuals responsible for making final decisions. The Crescent City Beacon Community, for example, vets technical decisions through a Health Information Technology Subcommittee. The subcommittee makes recommendations to the Administrative Committee (the oversight and decision-making body of GNOHIE) regarding the information systems and administration, infrastructure, and standards that support the GNOHIE. Specific examples of recommendations include vendor scoping and negotiations, care coordination intervention development and implementation, management of sensitive data, and patient consent.

In addition to streamlining the decision-making process, this focused input can help stakeholders with little technical experience feel more comfortable committing to proposed evaluation criteria or technology solutions. The Greater Tulsa Health Access Network Beacon Community, for example, released a request for proposal (RFP) with input from stakeholders, and the governance body also established a smaller workgroup including technology subject matter experts, clinicians, and privacy compliance officers to evaluate proposals against the requirements. Similarly, the Crescent City Beacon Community also found it helpful to approach stakeholders, including community physicians, for input into use cases. This helped the governance body, as well as the vendors, understand the immediate priorities for the community and helped less technical community members better evaluate vendor proposals.

The governance body establishes and manages to a timeline an equitable process for decision making, resolving conflicts, and communication. The timeline may allocate time to tasks such as

evaluation criteria, vendor and partner selection, use of standards, and phasing strategies. A clear, well-documented process and timeline keeps the implementation moving forward.

Maintaining open lines of communication with staff and key stakeholders and keeping them informed about project status is an important part of change management. While the governance body, key stakeholders, and community leaders often have the most influence on technology decisions, keeping staff informed and involved from the beginning can improve implementation and adoption of the new tools. Maryland CRISP emphasized the importance of transparency across the community when selecting new vendors or acquiring new services to enhance the community's HIE capabilities. This included transparency about the overall process, scoring, and RFP. The transparency encouraged members to openly share their input while also gathering input as the process evolved. Feedback was captured via both in-person and individual meetings to make sure consensus was achieved throughout the process.

### *Evaluating Technology and Vendors*

Technology evaluation criteria may apply to both strategic technology decisions (e.g., having a centralized, federated, or hybrid exchange model) and selecting vendors that will support it. Evaluation factors include the following:

- **Existing services.** The technology scan informs communities as to whether existing members or potential partners have access to shareable systems or services. Sharing systems and services, rather than acquiring new, can be more cost-effective. The governance body may need to evaluate the requirements for using these systems – for example, a new data use agreement or contributing funding – and perform a cost-benefit analysis against acquiring a new system.
- **Short- and long-term goals.** If the community's goals, value proposition, and proposed use cases do not include providing a centralized data repository, it may choose to invest in other systems in the near term. Communities may also consider long-term goals, even if out of scope initially, to mitigate the risk of making fundamental decisions that will not meet the needs of planned future services.
- **Cost and ease of implementation.** In addition to evaluating pricing, communities may choose to prioritize existing services or open-source services and standards (such as Direct or CONNECT) over new development or acquiring a proprietary system.
- **Sustainability, scalability, and benefits realization.** In addition to cost and benefits realization, communities evaluate the technology's long-term prospects and ability to meet the data needs of a fully live community – for example, focusing on products with open application programming interfaces (API) that allow for simpler connections and mitigate the risk of vendor lock. Vendor lock happens when an organization is unable to easily switch software and is prevalent when a vendor uses "hard coded" or custom connections to other systems to exchange data. It increases the risk to the organization if the vendor, for example, goes out of business or stops supporting a module in the future because it is resource intensive to replace it. A community must weigh establishing a long-term and sustainable IT infrastructure with targeting low-hanging fruit that demonstrates value quickly to stakeholders.

- **Human resources.** Organizations may be constrained in the number and complexity of new systems they can implement based on the number of staff who can implement the tools. They may also decide to focus on particular systems if the community already has a strong knowledge capacity for those tools.
- **Vendor certification.** Vendors may be certified, for example, to connect to the eHealth Exchange or accredited by DirectTrust, which is valuable for organizations that plan to use those services.
- **Past experience.** Decision makers will consider the experience of individual members and their vendors with the approaches being considered, as well as recommendations from other organizations that have attempted the same projects.

### *Evaluating Standards*

In addition to decisions on strategic technology and vendors, the participating entities may consider the effect these decisions have on standards for exchange. In terms of evaluating standards, stakeholders can consider national standards (e.g., Direct, the eHealth exchange), standards established by a standards developing organization (SDO) that have broad acceptance (e.g., HL7, SNOMED), or look to standards developed as part of the meaningful use requirements and the ONC S&I Framework as an effective starting place. In addition, a majority of participants or a dominant actor within the community may use a particular standard. Stakeholders may evaluate these standards to determine whether they align with established guidelines or future trends.

### *Evaluating Phasing Strategies for Technology Implementation*

In addition to considering solutions, the governance body may consider and make decisions regarding the sequence in which the community will roll out new functionality and integrate participating organizations. Rather than launching everything at once, the Beacon Communities focused on piloting features and functionality before making them widely available. Many of the same considerations for technology apply to phasing strategies – such as costs, benefits realization, and human resources. Vendors will also bring recommendations for successful phasing strategies. The governance body may consider, for example:

- **Logical technology groupings.** The community may need to implement core HIE infrastructure components together to function.
- **Logical use case workflow groupings.** Consider who will send and receive information. An organization planning to use ADT-based alerts, for example, may choose to incorporate it into a project to implement Direct emails.
- **Benefit to users.** Community leadership may choose to focus on a few clinician- or patient-facing “quick wins” to prove the value of the enhanced HIE capability. Alternatively, leadership may decide to first focus on back-end improvements or small pilots to avoid disruptions to clinical workflows.

- **Concurrent projects.** Enhancing existing initiatives – for example, a data quality improvement project at a large physician practice – adds to the value proposition for the new service and potentially conserves resources.
- **Super users.** Piloting functionality with a highly engaged group of users or an organization with highly sophisticated electronic systems can be helpful as these super users can provide feedback and demonstrate the benefits before the functionality rolls out to additional locations.

#### Key Considerations for a Governing Board

- Will stakeholders agree to reveal information about their health IT systems to support development of an actionable IT strategy?
- Will stakeholders consent to an actionable technology strategy?
- Will stakeholders buy into credible processes for selecting a technology vendor?
- Who will be empowered to make strategic and tactical technology decisions?
- In what sequence will enhancements be deployed to participating organizations?

### Strategic Objective 5: Define Measures, Monitor Progress, and Evaluate Success

Building upon the vision and goal setting discussed as part of Objective 1, a critical part of planning for expansion of HIE capabilities includes looking at the goals for the project and using those goals as a driver for how to measure success. Beacon Communities emphasized the importance of beginning to think about measurement early to ensure adequate time for stakeholder engagement and to proactively demonstrate a project’s progress toward providing value to various stakeholders. In practice, the Beacon Communities found it is necessary to continue this process in parallel with other planning and implementation activities.

Measure selection will likely prove challenging; selected measures must have stakeholder buy-in, be technically feasible, demonstrate the performance of new HIE capabilities, and meet the participants’ quality measurement needs. While clinical staff is likely to be most interested in clinical process or outcome measures, such as patients with glucose measurements within recommended limits, as a measure of the value of exchanging health information, the governance body may prioritize operational measures, such as the number of transactions, to best demonstrate the value of HIE for participating entities. A robust measurement and evaluation program will include both, with operational metrics to assess adoption and use of new technology, and clinical process and outcome measures to demonstrate longer-term effect.

This section addresses the value of securing stakeholder signoff on planned measurement activities and important steps for stakeholder involvement when prioritizing measures.

1. Create a plan for getting stakeholder buy-in on measurement goals and measures.
2. Define measures to gauge progress.

### 5.1 Create a Plan for Getting Stakeholder Buy-In on Measures and Measurement Goals

Engaging stakeholders throughout the measure selection process is essential. Each of the Beacon Communities built consensus across stakeholders on how to evaluate and communicate the effectiveness of specific programs. In most cases, a dashboard of measures were tracked and shared at the governance level. A focus on demonstrating the value of services provided to stakeholders supports a strong business model.

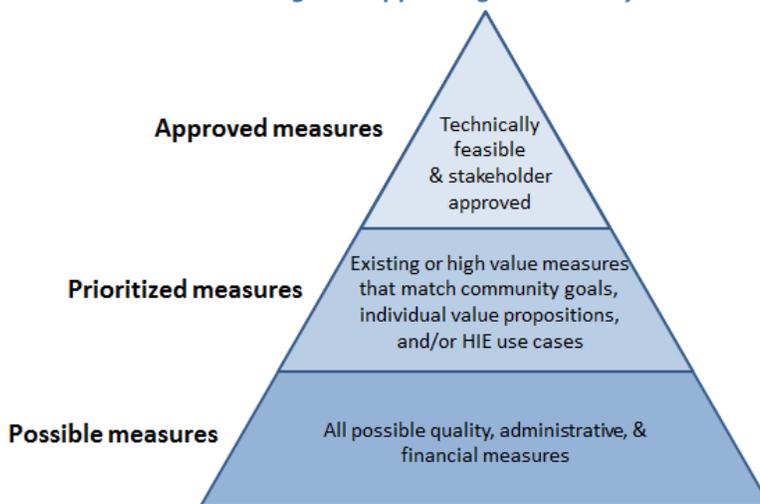
The governance body is well served by beginning the measurement selection process with efforts to learn which performance measures are most valuable to stakeholders, and then assess the cost and feasibility of producing high-priority measure results with vendors. A vendor contract can include data analysis and report generation to present results via a dashboard or other display. If the preferred exchange vendor does not have this capability, the community may consider contracting with a data analytics vendor or service provider for this purpose.

The Beacon Communities encouraged governance bodies to create a mitigation approach to help stakeholders make progress on crucial decisions. After agreeing to high-level measurement goals, for example, participants can expect to revisit specific measures throughout the implementation, as technical limitations may surface that could interfere with planned reporting. At a minimum, establish a monitoring and evaluation plan and get stakeholder signoff to minimize implementation delays.

### 5.2 Define Measures to Gauge Progress

The process of defining measures includes three steps: identifying the possible measures, prioritizing the measures based on the community’s goals, and getting stakeholder approval on the final set of measures (Exhibit 16).

*Exhibit 16: Prioritizing and Approving Community Evaluation Measures*



To help with strategic decision making and prioritization, stakeholders can consider guidelines such as:

- Clinical priorities.
- Stakeholder HIE value propositions.
- HIE use cases and how information will drive clinical transformation.
- How goals are aligned with the community's population health, public health, health improvement, meaningful use, and performance improvement goals.
- Existing measures and planned or in progress measurement activities.

While deciding on the ideal set of measures and getting stakeholder approval, measure feasibility may constrain the governance body. Measurement can require a variety of data collection methods, including automated reports, manual review, and surveys. Appendix D: includes a list of proposed measures for the Southeast Minnesota Beacon Community Health Information Exchange Transition to Practice (HIETOP) program. These measures could require a variety of collection processes, and some were flagged as tentative while community members determined whether and how they could track the requested items.

Some measures may not fit into the initial scope because of EHR limitations, exchange limitations, or limitations in the necessary analytics software. It is critical that stakeholders consider how to generate measurement reports before beginning, and whether the community needs to acquire additional analytic capabilities. Reporting capabilities can be challenging to acquire or enhance; considering this challenge early on reduces the risk that the community will complete the implementation and not be able to measure its success.

The quality of the data in electronic systems also affects the quality and accuracy of measure results. The Hawaii Island Beacon Community noted, for example, that its initial data sets feeding into the analytics tool were inconsistent and unreliable. It focused its efforts on practice redesign, training physicians and their office staff in meaningful use of their EHRs, which included mapping key data elements for exchange to EHR workflows, resulting in increasingly reliable and usable data. Communities may consider a phased approach to measure reporting, particularly in cases where there are data quality issues to address. Finally, selected measures should be thoroughly documented.

### *Operational and Clinical Measures*

Different measures will be of interest to different audiences. A robust measurement program will include both clinical and operational measures. The governing body may initially be focused on operational measures, which will demonstrate the extent to which participants are using HIE. While these will remain of interest over time, particularly if new functionality is expanded to a broader population of providers, community stakeholders will be more interested in improvement in clinical measure results over the longer term.

### *Operational Measures*

Operational or process measures track use of the newly established or enhanced systems and HIE-enabled information. Participants may also infer from operational measures how well the HIE

supports the clinical workflow because these influences will be reflected by changes in system usage, quality, and performance measures. Operational measures can cover a vast array of indicators, from system response time to number of participants and user satisfaction (see Exhibit 17 for sample operational measures).

*Exhibit 17: Sample Operational Measures for HIE Capabilities*

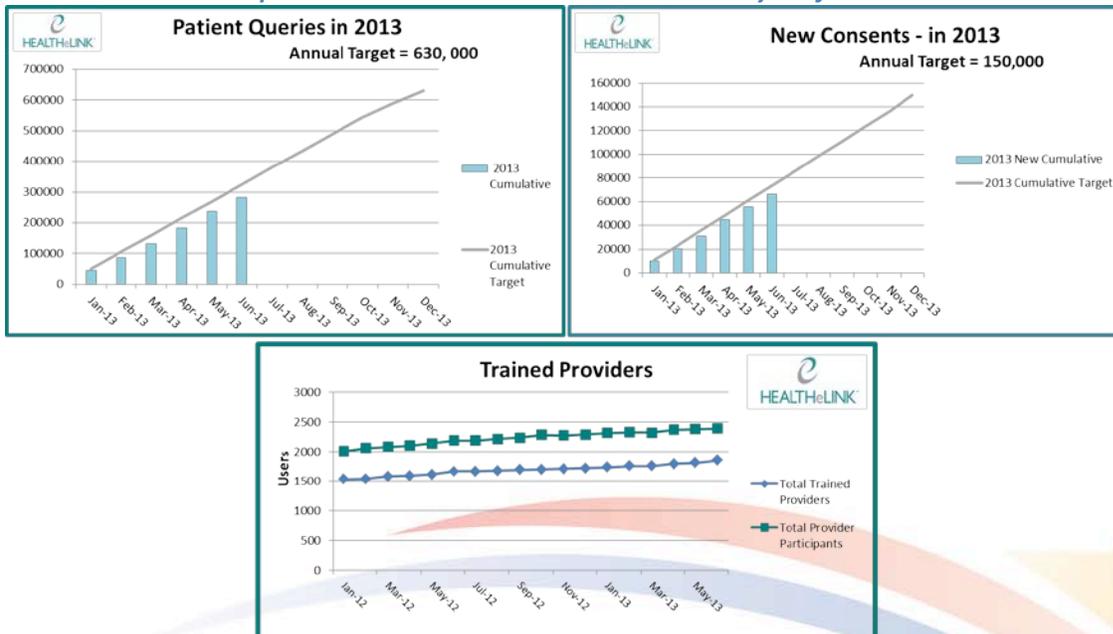
Type	Sample Measures
<b>Transactions</b>	<ul style="list-style-type: none"> <li>• Number of participating organizations (individually and by type).</li> <li>• Number of users (by physicians and clinical staff in total and over past 30 days).</li> <li>• Number of unique patients (over past 30 days).</li> <li>• Number of queries (aggregate and by organization).</li> <li>• Number of matches.</li> <li>• Number of unique documents exchanged (by type).</li> <li>• Number of users who log into a provider portal.</li> </ul>
<b>System Performance</b>	<ul style="list-style-type: none"> <li>• System response time.</li> <li>• System stability/downtime.</li> <li>• Number of messages returned due to “Patient Not Found.”</li> <li>• Number of messages returned due to “Provider Not Found.”</li> <li>• Storage space used.</li> <li>• Average transaction size.</li> </ul>
<b>User Satisfaction</b>	<ul style="list-style-type: none"> <li>• User satisfaction survey results (e.g., information accessible, accurate, timely, useful).</li> <li>• Number and frequency of communications/materials sent to staff/stakeholders.</li> </ul>
<b>Privacy and Security</b>	<ul style="list-style-type: none"> <li>• Number of patients that opt out of consent to release via HIE.</li> <li>• Number of privacy incidents related to HIE.</li> <li>• Number of security incidents related to HIE.</li> </ul>
<b>Analytics</b>	<ul style="list-style-type: none"> <li>• Number of reports generated.</li> <li>• Most frequently generated reports.</li> <li>• Average time to generate reports.</li> </ul>
<b>Administrative</b>	<ul style="list-style-type: none"> <li>• Open help desk tickets (by issue severity).</li> <li>• Number of dedicated and part-time staff.</li> <li>• Number of dedicated and part-time contractors.</li> <li>• Budget for HIE.</li> <li>• Number of participating entities attesting for meaningful use.</li> <li>• Number of future sites waiting to be brought live on functionality.</li> </ul>

The right operational measures can provide data that proves the value of the HIE to individual stakeholders and the community as a whole. For example, a 2012 study by Audacious Inquiry found that HIOs benefited from shifting the focus of measures from the number of participating organizations to the number of records and numbers of queries and transactions because it better indicated progress toward a tipping point of turning HIE into a clinical necessity:

*The volume of queries into an HIO is an important metric for gauging progress towards the tipping point. It is also frequently used as a proxy for value/success measurement (i.e., if the HIO continues to be queried it must be producing value). There are certainly issues with using that metric as a value proxy, such as in the case of an HIO that has established automated queries into the network upon a patient registration or visit. There are other measures, such as the percentage of queries that (a) result in a patient being found and (b) result in a clinical document being reviewed (i.e., query hit rate, document open rate) that can be more appropriate for measuring utilization. However, HIOs are challenged in delivering increasing rates of utilization. Low utilization volumes or stagnant growth can similarly be noted as an indicator of a value deficiency.<sup>xlv</sup>*

The Western New York Beacon Community, for example, tracks operational measures on a monthly basis and includes the number of patient queries, new consents, cumulative consents, community records exchanged, trained providers, exchanged CCDs, and number of practices receiving results by EHR (see Exhibit 18 for example measure results).

**Exhibit 18: Sample Western New York Beacon Community Performance Measures**



In addition to validating value propositions, tracking the right performance measures enables the identification of gaps in performance. With problem areas clearly identified, staff can make mid-course corrections as necessary to achieve program goals.

Exhibit 19 illustrates potential gaps that can be identified as a result of monitoring operational measures.

*Exhibit 19: Common Gaps Identified by Measurement Activities*

Gap	Characteristics to Measure
<b>Trust</b>	<ul style="list-style-type: none"> <li>Adoption of policies, procedures, and other mechanisms that help ensure trusted exchange.</li> <li>Perceptions of trust among key participants.</li> </ul>
<b>Interoperability</b>	<ul style="list-style-type: none"> <li>Track HIE activity across a variety of domains.</li> <li>Track gaps in exchange of health information.</li> </ul>
<b>Cost and Complexity</b>	<ul style="list-style-type: none"> <li>Costs associated with exchange.</li> <li>Provider perceptions regarding costs and complexity of HIE as barriers.</li> <li>Conditions that could lead to high cost and/or complexity of HIE.</li> </ul>

**Greater Tulsa Health Access Network: Measuring Use of the HIE**



- The Tulsa Beacon Community values performance measurement and has taken the initial steps to evaluate the effect HIE has on different indicators. Usage measures Tulsa is focused on include: How many people (e.g., patients, physicians, and administrators) are logging in?
- How many accounts are active?
- How often are they logging in?
- How many patient records are being accessed?

Regular monitoring of usage patterns is also vital to Tulsa’s evaluation process, allowing it to react to performance data.

**Clinical Process and Outcome Measures**

Clinical measures look at the community’s progress toward meeting quality, efficiency, or other administrative goals. Communities can expedite the process of selecting measures if they can align HIE measurement efforts with community-wide initiatives (e.g., payment reform, performance improvement, public health goals, and meaningful use). For example, a measure of success can be a practice’s success rate for helping patients manage diabetes, standard measures set by the Joint Commission, or meaningful use clinical quality measures.

According to a 2012 study of HIOs, most representatives surveyed agreed that HIE yielded value in terms of quality improvement and return on investment. The metrics they felt were the most compelling in explaining the ROI were typically reduction of duplicative tests; better coordination of care for patients with chronic conditions; and decreased readmission. Those surveyed also cited quality of care improvements in the domains of patient-centered care, efficiency, and safety.<sup>xlvi</sup>

Enabling reporting of clinical quality and outcome measures can also be valuable as a service to participants. The Tulsa Beacon Community noted that analytics has been a top value-added service for the MyHealth Access Network, and considers it a key driver of future sustainability due to the interest of large health systems to participate and provide funding. With the pressures of payment reform and the emergence of ACOs – where providers are accountable for costs and outcomes associated with patients seeking care beyond their immediate network – having access to data at a community level provides a more comprehensive picture of a patient’s care.

While outcome reporting can add value for members, it may be uncomfortable sharing performance data with competing organizations. Some Beacon Communities resolved this by creating individual and aggregated quality reports with the names of other clinics hidden; each facility received its performance against the baseline for the community.

Stakeholders across the country, including the Beacon Communities, also continue to wrestle with the challenges of developing a causal relationship between HIE and improved care outcomes because a wide range of factors, of which HIE is one component, may influence clinical improvements. As a result, outcome-based measures may not always be the most successful mechanism for demonstrating the value of the HIE. More work is needed to establish the correlation between HIE and patient outcomes.

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### Sample Tulsa Beacon Community HIE Clinical Process and Outcome Measures

- Duplicate laboratory testing: HbA1C
  - Duplicate laboratory testing: lipid panel
  - Admissions for CHF, COPD, asthma
  - Emergency department visits for CHF, COPD, asthma
  - Duplicate laboratory testing: microalbuminuria
  - Influenza immunization
  - Pneumonia vaccination
  - Mammography screening
- 

#### Key Considerations for a Governing Board

- How will the organization define success?
- What measures are needed to satisfy current and potential future stakeholders?
- Will the community use an internal or external evaluator to measure success?
- How will the organization use the measurement data?
- What capabilities are needed to run measurement reports?

## Looking Ahead

The health care landscape has continued to evolve in the last several years. The Affordable Care Act has accelerated the shift from pay-for-volume to pay-for-value, which is driving the need for aggregation of patient health information from multiple sources. To support new payment models and manage cost, utilization, and quality of care for a patient, organizations that create networks to manage cost and quality realize that health information needs to follow a patient to where they receive care. Data exchange, therefore, is vital to shift the needle.

Over the past three years, both private and public investment continued to expand the number of providers and hospitals using EHR technology and the number of participants exchanging data. While early exchange efforts needed to invest in costly new infrastructure between incompatible systems, communities seeking to enhance their exchange capabilities can now build upon a variety of established initiatives developed as part of the HITECH investment in state exchange capabilities and other efforts to expand national exchange.

As the path for HIE sustainability continues to evolve, communities are encouraged to pursue HIE infrastructure options that support local goals and align with financial realities. For example, light-weight infrastructure options enable communities to continue to provide HIE services but maintain flexibility and control costs. Communities should continue to look at all existing infrastructures including those offered by payers and possible adjoining states or regions. However, in the future, traditional exchange models and vendors may be supplanted by those offering open-source software that allows the flexibility to develop needed customizations. In addition, communities may use shared services models that will allow sharing of critical services among many organizations – e.g. master patient indices, record locator services, and provider directories – which, in turn, will drive down costs. Although both point-to-point (Direct protocol) and data repositories will continue to be relevant, architectures may move toward supporting specific value propositions and specific clinical transformation efforts (e.g., focus on transitions of care vs. utilization reporting). In addition, data warehouses and central data repositories may shift from local environments to the cloud as communities continue to add more data to the value set that is needed to manage care in light of payment reform.

The Beacon Community Program has been at the forefront of efforts to use HIE to advance local quality, cost, and population health goals. Their experiences and lessons learned provide valuable information that other interested communities can use when considering their own HIE strategies. As the market, political, and regulatory environments continue to evolve, the *Enabling Health Information Exchange to Support Community Goals* Learning Guide and its five Strategic Objectives offers key insights and practical guidance for communities seeking to successfully implement HIE to support their community goals into the future.

## Appendices

### Appendix A: Summary of Key Decision Points Facing the Lead Convening Entity or Governing Board

*Exhibit A-1: Key Considerations in Achieving Strategic Objectives*

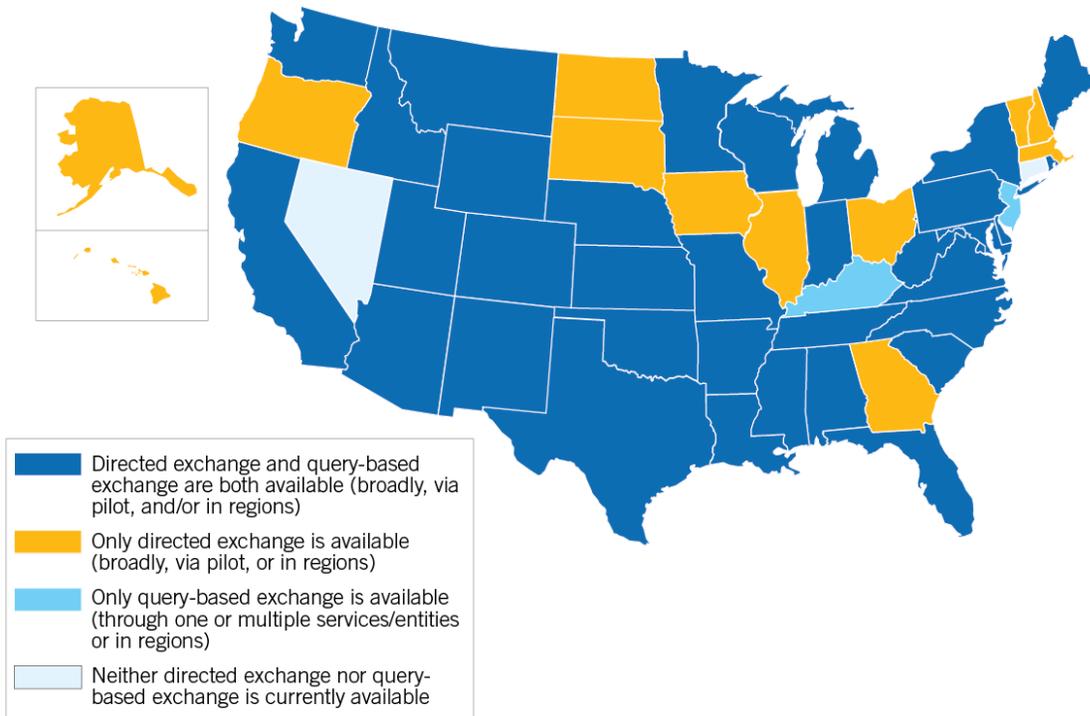
Strategic Objective	Key Considerations
<p>1. Convening Stakeholders and Developing a Governance Structure to Foster Trust and Sustain Collaboration</p>	<ul style="list-style-type: none"> <li>• Who are the key stakeholders and what are their current relationships?</li> <li>• What strategies are needed to convene partners and stakeholders?</li> <li>• What stakeholder needs can be addressed by HIE?</li> <li>• Who are the champions that will commit time and energy to continuing development?</li> <li>• Will stakeholders come together to articulate, own, and generate support for the common vision?</li> <li>• Will stakeholders agree to the clinical transformation scenarios that they wish to work toward in the near term?</li> <li>• What corporate structure should be established to best meet the community’s needs, to have the best chance of ensuring that participating entities are accountable for sharing data according to nationally established standards, and to provide financial sustainability?</li> <li>• What should the governance structures and processes to maintain ongoing collaboration look like?</li> <li>• How will stakeholders realize when their needs are met or value is realized?</li> </ul>
<p>2. Creating a Legal Framework for Sharing Protected Health Information</p>	<ul style="list-style-type: none"> <li>• Will stakeholders commit the resources needed to establish a strong and effective legal framework?</li> <li>• Will stakeholders encourage their legal representatives to find solutions rather than problems?</li> <li>• How will the governance body and participating organizations enforce policies that protect the confidentiality of patient information?</li> <li>• Will stakeholders execute the agreements and change their workflow process and documentation requirements to enable full use of the HIE?</li> <li>• Who will provide training for HIE staff and participating entities?</li> </ul>

Strategic Objective	Key Considerations
<p>3. Identifying Funding Sources and Defining the Financing Strategy</p>	<ul style="list-style-type: none"> <li>• What startup funding sources should communities target for planning, design, and implementation of HIE?</li> <li>• How do the cost and revenue model results inform selection of HIE services and associated financing and pricing strategies?</li> <li>• What HIE financing strategies should the community use for planned services?</li> <li>• What pricing strategy should the community use for these services?</li> <li>• How can the community proactively address financial challenges throughout the planning, design, and implementation process?</li> </ul>
<p>4. Defining Available Technology Paths to Facilitate Data Sharing</p>	<ul style="list-style-type: none"> <li>• Will stakeholders agree to reveal information about their health IT systems to support development of an actionable IT strategy?</li> <li>• Will stakeholders consent to an actionable technology strategy?</li> <li>• Will stakeholders buy in to credible processes for selecting a technology vendor?</li> <li>• Who will be empowered to make strategic and tactical technology decisions?</li> <li>• In what sequence will enhancements be deployed to participating organizations?</li> </ul>
<p>5. Defining Measures, Monitoring Progress, and Evaluating Success</p>	<ul style="list-style-type: none"> <li>• How will the organization define success?</li> <li>• What measures are needed to satisfy current and potential future stakeholders?</li> <li>• Will the community use an internal or external evaluator to measure success?</li> <li>• How will the organization use the measurement data?</li> <li>• What capabilities are needed to run measurement reports?</li> </ul>

### Appendix B: State HIE Cooperative Agreement Program Exchange Models

The State HIE Cooperative Agreement Program launched in February 2010 is designed to promote HIE across the health care system and “aims to facilitate and expand the secure electronic exchange of health information among organizations according to nationally recognized standards.”<sup>xlvii</sup> The Office of the National Coordinator for Health Information Technology (ONC) administers the program in partnership with states focusing on helping states and state-designated entities (SDE) support providers to achieve meaningful use goals, objectives, and measures as it relates to HIE. State HIE Cooperative Agreement Program awardees consist of a total of 56 states, eligible territories, and qualified SDEs. By early 2012, all awardees had launched implementation activities to enable statewide exchange. Exhibit B-1 displays the combined directed exchange and query-based exchange implementation status for all state HIE awardees in calendar quarter one of 2013.

*Exhibit B-1: State HIE Awardee Exchange Mechanisms (Q1 2013)*



Source: Adapted from U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. State Health Information Exchange Program. “State HIE Implementation Status.” Available at: <http://statehieresources.org/program-measures-dashboard/hie-implementation-status/>.

## Appendix C: Sample Data Use Agreement

### *Sample Beacon Community Data Use Agreement*

#### *Data Share*

This Beacon Data Use Agreement is by and between the [Beacon Community Entity], a/an [State] not-for profit corporation located at [address] and XXXXXX, a/an [State] not-for-profit corporation with principal offices at, [address], (“Hospital”).

#### **RECITALS**

1. [BEACON COMMUNITY ENTITY] has been awarded a grant by the US Department of Health and Human Services, Office of the National Coordinator for Health Information Technology (“ONC”) funding three demonstration projects for the purpose of determining how to improve health care quality and costs with respect to pediatric asthma and adult diabetes patients (“Beacon Demonstration Projects”).
2. Specific physician practices have been identified and have agreed to participate in the Beacon Demonstration Projects (“Beacon Practices”) with respect to their patients who have been diagnosed with pediatric asthma in exchange for: (1) the provision of certain patient information, specified herein, which will aid in the treatment of their patients; and, (2) data aggregation and analysis services for quality assessment and improvement purposes
3. The improvement initiatives proposed as part of the Beacon Demonstration Projects include the provision of Admissions, Discharge and Transfer data to the respective Beacon Practices when patients under their care are treated at a Hospital emergency department or an urgent care facility, or are admitted or readmitted to a Hospital (“Encounter Data”); and aggregation of Encounter Data to produce cost and quality metrics.
4. The Hospital data may contain Protected Health Information (“PHI”) as defined in Health Insurance Portability and Accountability Act of 1996, as amended, including the American Recovery and Reinvestment Act of 2009 (“ARRA”) and the Health Information Technology for Economic and Clinical Health Act (“HITECH”), and all implementing regulations (collectively “HIPAA”).
5. HIPAA permits a Covered Entity, as that term is defined by HIPAA, to disclose PHI to another Covered Entity for the purposes of treating the patient. A Covered Entity may engage a Business Associate to disclose the PHI on behalf of the Covered Entity so long as a Business Associate Agreement has been executed between the Covered Entity and the Business Associate and the disclosure is in compliance with HIPAA. Further, HIPAA permits a Covered Entity to disclose PHI to its Business Associate to aggregate data belonging to multiple Covered Entities for the purpose of health care operations including quality assessment and improvement activities of the Covered Entities. Hospital is a Covered Entity and [BEACON COMMUNITY ENTITY] is a Business Associate of Hospital, as those terms are defined in the HIPAA Privacy Regulations.
6. [BEACON COMMUNITY ENTITY] has entered into a Business Associate Agreement with Hospital under which the use of the Encounter Data is expressly limited. Under HIPAA, Hospital may authorize

[BEACON COMMUNITY ENTITY] to disclose the Encounter Data to the applicable Beacon Practices (which are also Covered Entities) for treatment or for quality assessment and quality improvement activities of the Beacon Practices provided the recipient has or had a relationship with the Hospital patient (“Shared Patients”). [BEACON COMMUNITY ENTITY] acknowledges and agrees that any data it discloses to the Beacon Practices for the purposes of quality assessment and quality improvement activities must meet the minimum necessary requirements of HIPAA.

7. Hospital desires to allow [BEACON COMMUNITY ENTITY] to disclose the Encounter Data to the Beacon Practices for purposes of treatment of the Shared Patients and to use the Encounter Data to aggregate and analyze the Encounter Data for the quality improvement initiatives described herein.

#### **AGREEMENT**

In consideration of the foregoing, and subject to the following terms and conditions, the parties to this Agreement mutually agree as follows:

1. Hospital authorizes the following in connection with the Beacon Demonstration Projects:
  - a. For purposes of treating the Shared Patients, Hospital authorizes [BEACON COMMUNITY ENTITY] to send notifications containing the Encounter Data to the applicable Beacon Practices when their Shared Patients, who have been identified by the Beacon Practices as having pediatric asthma, experience an emergency department encounter, an urgent care encounter, or a Hospital admission or readmission.
  - b. For the purposes of quality assessment and quality improvement, Hospital authorizes [BEACON COMMUNITY ENTITY] to aggregate and analyze the Encounter Data by physician practice for the Shared Patients, who have been identified by the Beacon Practices as having pediatric asthma and to provide the aggregated results to Hospital and the Beacon Practices.
  - c. Hospital authorizes resulting de-identified aggregated data to be provided to ONC on a quarterly basis.
2. Encounter Data will be used solely for the purposes described herein and no further use will be made without the express written authorization by Hospital.

#### **[BEACON COMMUNITY ENTITY] OBLIGATIONS**

1. The Encounter Data used in the Beacon Demonstration Project will be housed by BEACON COMMUNITY ENTITY in a secure environment. While under the control of BEACON COMMUNITY ENTITY, at all times, the Encounter Data will be kept confidential and secure, in compliance with the Security and Privacy Rules of HIPAA, as amended, and as provided in a Business Associate Agreement executed by the parties.
2. Ownership of Encounter Data provided by Hospital will at all times remain with Hospital.
3. The Encounter Data will be used solely for the purposes described herein and no further use or disclosure of the data will be made without the express written authorization of Hospital. Any further use of the data for publication or research will be undertaken only upon satisfaction of appropriate regulatory compliance including IRB waiver or approval, as applicable, and express written authority of Hospital Practice.

**TERM AND TERMINATION**

- 1. This Agreement is effective beginning on the Effective Date and ending upon the expiration of the Beacon Demonstration Project which is estimated to be September 30, 2013, unless terminated earlier in accordance with this Agreement.
- 2. If the term of the Beacon Demonstration Projects is extended, Hospital agrees to extend the term of this Agreement to allow the completion of the Beacon Demonstration Projects, provided that timely notice of the extension period is provided in writing to Hospital and written authorization of all parties is obtained.
- 3. Hospital may terminate this Agreement at any time upon thirty (30) days written notice to BEACON COMMUNITY ENTITY at the address provided above.

**MISCELLANEOUS**

- 1. This Agreement will be governed by and construed in accordance with the laws of the State of [State’s name] without reference to or application of its conflict of laws rules or principles.
- 2. Notices required or permitted under this Agreement must be in writing and shall be delivered by courier or certified mail, and, in each instance, will be deemed given upon receipt. All communications will be sent to the addresses set forth in the first paragraph above unless another address is specified in accordance with this paragraph. Notices sent to Hospital will be sent to the attention of XXXXXXXXX.

**EFFECTIVE DATE**

This Agreement is effective	this [Date].
[Beacon Community Entity].	XXXXXXXXXX:
By: _____	By: _____
Its _____	XXXXXXXXXX:
Date: _____	Date: _____

## Appendix D: Sample Evaluation Measures

### Exhibit D-1: Proposed Southeast Minnesota Beacon Community Health Information Exchange Transition to Practice (HIETOP) Measures

Type	Measures	
<b>Technical Outcomes</b>	<ul style="list-style-type: none"> <li>System response time.</li> <li>Number of queries.</li> <li>Number of matches.</li> <li>Number of unique documents exchanged, received, and returned.</li> <li>Number of false positives.</li> <li>Number of false negatives.</li> <li>System stability/downtime.</li> <li>Help desk accessibility for HIE issues.</li> <li>Help desk interventions for HIE.</li> <li>Outbound requests.</li> <li>Outbound gateways contacted.</li> <li>Outbound gateways responding.</li> </ul>	<ul style="list-style-type: none"> <li>Outbound gateways “Patient Not Found.”</li> <li>Outbound “Patient Found” with zero documents.</li> <li>Outbound “Patient Found” with one or more documents.</li> <li>Outbound documents returned for patients.</li> <li>Inbound first-time patient discovery.</li> <li>Inbound “Patient Not Found” (no patient).</li> <li>Inbound “Patient Not Found” (more than one patient).</li> <li>Inbound “Patient Not Found” (no consent).</li> <li>Inbound patient discovery.</li> <li>Inbound document queries.</li> <li>Inbound document retrieval.</li> </ul>
<b>Clinical Outcomes</b>	<p><b>Quality</b></p> <ul style="list-style-type: none"> <li>Information accessible (user survey).</li> <li>Information accurate (user survey).</li> <li>Information timely (user survey).</li> <li>Information useful (user survey).</li> </ul> <p><b>Safety</b></p> <ul style="list-style-type: none"> <li>Improves patient safety.</li> <li>Reduces errors.</li> <li>Introduces errors.</li> </ul>	<p><b>Care Coordination</b></p> <ul style="list-style-type: none"> <li>Triage process in different sites.</li> <li>Data available Continuity of Care Document (CCD) or fax.</li> <li>ER visits decreased.</li> <li>Hospital readmission within 30 days decreased.</li> </ul>

Type	Measures	
<b>Operational Outcomes</b>	<p><b>Clinical Efficiency</b></p> <ul style="list-style-type: none"> <li>• Reduces duplicate testing.</li> <li>• Positive patient experience.</li> <li>• Provider satisfaction.</li> <li>• Ease of use for clinical assistants.</li> <li>• Medication reconciliation.</li> </ul> <p><b>HIM Efficiency</b></p> <ul style="list-style-type: none"> <li>• Availability of CCD.</li> <li>• Time to load CCD.</li> <li>• Number of requests broken down by entity.</li> <li>• Number of CCD information that was received through other means.</li> <li>• Quality of CCD.</li> </ul> <p><b>Utilization and Usage</b></p> <ul style="list-style-type: none"> <li>• Number of providers using HIE.</li> <li>• Number of clinical staff using HIE.</li> <li>• Number of CCDs exchanged.</li> <li>• Other documents exchanged.</li> </ul> <p><b>Financial</b></p> <ul style="list-style-type: none"> <li>• Budget for HIE.</li> <li>• Return on investment and number of staff doing release of information over time.</li> <li>• Meaningful use attestation.</li> </ul>	<p><b>Privacy, Compliance, and Data Security</b></p> <ul style="list-style-type: none"> <li>• HIE consent process.</li> <li>• Number of patients that opt out of consent to release via HIE.</li> <li>• Release of information (all).</li> <li>• Break the Glass (describes situations in which a health care provider receives access to a patient’s records without a patient’s consent, often due to an emergency situation). In EHRs this can also refer to specific functionality that allows a care provider to access charts that they would not normally have permissions for and which are tracked on privacy and security audit reports.</li> <li>• Fax/mail versus electronic consent.</li> <li>• Number of privacy incidents related to HIE.</li> <li>• Number of security incidents related to HIE.</li> </ul> <p><b>Communication (Target Audience for HIE)</b></p> <ul style="list-style-type: none"> <li>• Results of provider survey.</li> <li>• Number and frequency of communications/materials sent to staff and stakeholders.</li> </ul> <p><b>Time and Motion Studies</b></p> <ul style="list-style-type: none"> <li>• Requesting health information.</li> <li>• Time health information is received.</li> <li>• Time provider reviews health information.</li> </ul>

## Appendix E: List of Acronyms and Key Definitions

### Exhibit E-1: Acronyms

Acronyms	
ACO	Accountable care organization
API	Application programming interface
BLUES	Better Living Utilizing Electronic Systems
CCBC	Crescent City Beacon Community
C-CDA	Consolidated Clinical Document Architecture
CDC	Centers for Disease Control
CDR	Central data repository
CHF	Congestive heart failure
CMS	Centers for Medicare and Medicaid Services
COPD	Chronic obstructive pulmonary disease
CPOE	Computerized physician order entry
CPT	Current Procedural Terminology
DICOM	Digital Imaging and Communications in Medicine
DoD	Department of Defense
DUA	Data use agreement
DURSA	Data use and reciprocal support agreement
ED	Emergency department
EHR	Electronic health record
EMR	Electronic medical record
HDL	<i>High-density lipoprotein</i>
HEDIS	<i>Healthcare Effectiveness Data and Information Set</i>
HHS	Department of Health and Human Services
HIE	Health information exchange
HIO	Health information organization
HIPAA	Health Information Portability and Accountability Act
HISP	Health Information Service Provider
HITECH	Health Information Technology for Economic and Clinical Health
HL7	Health Level 7
LDL	Low-density lipoprotein
LOINC	Logical Observation Identifiers Names and Codes
MPI	Master patient index

Acronyms	
MQIC	Michigan Quality Improvement Consortium
MU	Meaningful use
NANDA	North American Nursing Diagnosis Association
NDF	National Drug File
NIC	Nursing Interventions Classification
NOC	Nursing Outcomes Classification
NwHIN	Nationwide Health Information Network
ONC	Office of the National Coordinator for Health Information Technology
PBM	Pharmacy Benefit Management
PCMH	Patient-Centered Medical Home
PHI	Personal health information
PHR	Personal health record
QHN	Quality Health Network
REC	Regional extension center
RLS	Record locator service
SaaS	Software as a Service
SNOMED	Systematized Nomenclature of Medicine
SOAP	Simple Object Access Protocol
SSA	Social Security Administration
VA	Department of Veterans Affairs
VODI	Voices of Detroit Initiative

*Exhibit E-2: Key Definitions*

Key Definitions	
<b>CONNECT</b>	Open-source software solution that supports health information exchange both locally and at the national level.
<b>Consumer-Mediated Exchange</b>	Ability for patients to aggregate and control the use of their health information among providers.
<b>Directed Exchange</b>	Ability to send and receive secure information electronically between care providers to support coordinated care.
<b>e-prescribing</b>	Ability for providers to electronically sign medication orders and transmit them to a patient’s pharmacy to be filled.
<b>Health Information Exchange</b>	The electronic movement of health-related information among organizations according to nationally recognized standards.
<b>Query-Based Exchange</b>	Ability for providers to find and/or request information on a patient from other providers, often used for unplanned care.
<b>RxNorm</b>	Provides normalized names for clinical drugs and links its names to many of the drug vocabularies commonly used in pharmacy management and drug interaction software, including those of First Databank, Micromedex, MediSpan, Gold Standard, and Multum.
<b>Services</b>	In software and systems architecture, <i>services</i> refer to functions and policies that can be reused within the same system or across multiple systems. Common examples include authentication and identity management.
<b>Service Provisioning Model</b>	In software and systems architecture, the service provisioning model refers to the approach by which a system or system(s) access services. Software as a service (SaaS) is a common example and refers to software that is rented rather than purchased.
<b>State Designated Entity (SDE)</b>	A state designated entity (SDE) may receive grants under the State Health Information Exchange Cooperative Agreement Program. Each SDE designated through a letter from the state’s governor. An SDE must be a not-for-profit entity with broad stakeholder representation on its governing board; demonstrate that one of its principal goals is to use information technology to improve health care quality and efficiency through the authorized and secure electronic exchange and use of health information; adopt nondiscrimination and conflict of interest policies that demonstrate a commitment to open, fair, and nondiscriminatory participation by stakeholders; and conform to such other requirements that HHS may establish. ( <i>American Reconstructive and Recovery Act, Public Law 111-5. Section 3013(f)</i> ).

## Appendix F: HIE Capability, Architecture, and Interoperability Standards— Resource List

The following resources introduce common HIE-related technologies and standards and are intended as a starting place for those new to HIEs. This appendix also provides other examples of HIE toolkits.

### General Resources

- Agency for Healthcare Research and Quality. (2010). *Evaluation toolkit health information exchange projects*. Available at [http://healthit.ahrq.gov/sites/default/files/docs/page/Revised\\_HIE\\_Toolkit.pdf](http://healthit.ahrq.gov/sites/default/files/docs/page/Revised_HIE_Toolkit.pdf).
- College of Healthcare Information Management Executives. (2011). *The HIE guide for CIOs*. Available at [http://www.cio-chime.org/hieguide/complete\\_hie\\_guide\\_for\\_cios.pdf](http://www.cio-chime.org/hieguide/complete_hie_guide_for_cios.pdf).
- Healthcare Information and Management Systems Society. (2009). *A HIMSS guide to participating in a health information exchange*. Available at [http://www.himss.org/files/HIMSSorg/Content/files/HIE/HIE\\_GuideWhitePaper.pdf](http://www.himss.org/files/HIMSSorg/Content/files/HIE/HIE_GuideWhitePaper.pdf).
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- National eHealth Collaborative. (April 2012). *Health information exchange roadmap: The landscape and path forward*.
- Markle Foundation. (2012). *Governance of health information sharing efforts: Achieving trust and interoperability with meaningful consumer participation*.
- The Office of the National Coordinator for Health Information Technology. (2013). *Governance framework for trusted electronic health information exchange*. Available at [http://www.healthit.gov/sites/default/files/GovernanceFrameworkTrustedEHIE\\_Final.pdf](http://www.healthit.gov/sites/default/files/GovernanceFrameworkTrustedEHIE_Final.pdf).
- West, D., and A. Friedman. (2012) *Governance studies at Brookings: Health information exchange and megachange*. Available at [http://www.insidepolitics.org/brookingsreports/health\\_info\\_exchange.pdf](http://www.insidepolitics.org/brookingsreports/health_info_exchange.pdf)
- *State HIE toolkit: Vulnerable populations and HIE*. Available at [http://www.ahima.org/downloads/pdfs/advocacy/VulnerablePopulationsModule-HIEToolkit-ONCFinalWithStateInfo\\_2010\\_11\\_16\(2\).pdf](http://www.ahima.org/downloads/pdfs/advocacy/VulnerablePopulationsModule-HIEToolkit-ONCFinalWithStateInfo_2010_11_16(2).pdf)
- National Rural Health Resource Center. *HIE toolkit (for rural communities)*. Available at <http://www.ruralcenter.org/tasc/content/hie-toolkit>

### Technology-Specific Resources

- Health Level 7. *Record locator service description*. Available at [http://www.hl7.org/search/viewSearchResult.cfm?search\\_id=336575&search\\_result\\_url=%2Fdocumentcenter%2Fpublic%2Fwg%2Fservicesbof%2FRecord%20Locator%20Integrated%20Description%20v0%2E9%2Edoc](http://www.hl7.org/search/viewSearchResult.cfm?search_id=336575&search_result_url=%2Fdocumentcenter%2Fpublic%2Fwg%2Fservicesbof%2FRecord%20Locator%20Integrated%20Description%20v0%2E9%2Edoc).
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- For more information about Direct and HISPs, see [directproject.org](http://directproject.org).
- For more information about the eHealth Exchange, visit [www.healthewayinc.org](http://www.healthewayinc.org), the website for the nonprofit organization that manages the exchange.
- For more information about Blue Button, see [www.va.gov/bluebutton](http://www.va.gov/bluebutton).
- For more information about messaging and terminology standards, see:
  - *Summary: Technology and Standards for Health Care*: <http://aspe.hhs.gov/sp/nhii/standards.html>
  - *Health Information Technology and Health Data Standards at NLM*: <http://www.nlm.nih.gov/healthit.html>

## Appendix G: Legal Framework—Resource List

- Indiana Health Information Exchange. (2012). *Building effective data governance models, policies and agreements in a HITECH world*. Available at <http://www.ihie.org/documents/buildingeffectivegovernancemodels.pdf>.
- Centers for Disease Control and Prevention. (2003). *HIPAA privacy rule and public health*. Available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm>.
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<sup>iii</sup> King, J., V. Patel, & M. F. Furukawa. (December 2012). *Physician adoption of electronic health record technology to meet meaningful use objectives: 2009–2012*. ONC Data Brief, no. 7. Washington, DC: Office of the National Coordinator for Health Information Technology.

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<sup>v</sup> Office of the National Coordinator for Health Information Technology. (June 2013). Update on the Adoption of Health Information Technology and Related Efforts to Facilitate the Electronic Use and Exchange of Health Information – A Report to Congress. Available at [http://www.healthit.gov/sites/default/files/rtc\\_adoption\\_of\\_healthit\\_and\\_relatedefforts.pdf](http://www.healthit.gov/sites/default/files/rtc_adoption_of_healthit_and_relatedefforts.pdf).

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