

EVALUATION OF THE BEACON COMMUNITY
COOPERATIVE AGREEMENT PROGRAM

Data Sharing to Enable Clinical
Transformation at the Community Level:
IT Takes a Village

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PRESENTED BY:

NORC at the
University of Chicago
4350 East-West Highway
Suite 800
Bethesda, MD 20814



at the UNIVERSITY *of* CHICAGO

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Introduction

In 2010, the Office of the National Coordinator for Health Information Technology (ONC) launched the three-year Beacon Community Cooperative Agreement Program, which provided \$250 million to 17 Beacon Communities across the country to invest in health information technology (IT) and health information exchange infrastructure. The Program also supports a variety of interventions, including care-delivery innovations, provider performance measurement and feedback initiatives, and tools for providers and consumers to enhance care. The Beacon Community Program serves as a capstone to other initiatives implemented under the Health Information Technology for Economic and Clinical Health (HITECH) Act as it aims to bring together the strands of other HITECH efforts to demonstrate how adoption and meaningful use of health IT can support clinical processes and outcomes. The Communities used this funding to work on the development and dissemination of health IT-enabled quality improvement practices that have been found to be effective in particular community and practice environments.

In 2011, ONC funded NORC at the University of Chicago (NORC) to conduct a four-year independent evaluation of the Beacon Community Program. This research brief presents findings from a series of site visits and telephone interviews with the Beacon Communities examining their approaches to and experiences with building and strengthening their health IT infrastructures, specifically with respect to successes and challenges related to the sharing of patient-specific information to improve clinical care.

Data Sharing Across the Beacon Communities

The 17 selected Beacon Communities covered a wide geographic area of the United States from Bangor, Maine, to Hilo, Hawai'i, and reflected a diversity of practice settings and health care challenges across the country. Although ONC selected these Communities in part because they were already established health IT users, they varied significantly in their levels of staff, financial resources, infrastructure, and stage of implementation and adoption of health IT, including their rates of electronic health record (EHR) adoption, which affected their ability to enable exchange.¹

Table 1 describes each of the Beacon Communities, including each Community's type of lead organization. Additionally, the table shows each Beacon's approach to data sharing and developing infrastructure to support it, specifically whether a Beacon was building new infrastructure—that is, minimal infrastructure existed prior to Beacon funding—or strengthening existing infrastructure. Seven Beacons focused on building this infrastructure largely from the ground up, while ten used program funding to strengthen or accelerate the expansion of existing systems for health information exchange. The table also shows how the Communities structured their data sharing platforms. In some states, Communities established centralized repositories for clinical data that providers could query for patient information, while others enabled point-to-point, directed exchange among providers. Many Beacons also used state or regional health information organizations (HIOs), organizations that oversee the exchange of health-related information among organizations, to facilitate data sharing. The dimensions expressed in Table 1 will be expanded upon throughout the brief.

¹ For additional information on how each Community differed based on various contextual and organization-level characteristics, types of interventions, levels of EHR adoption among hospitals and ambulatory care providers, e-prescriptions, and HIO participation in each Beacon Community, see http://www.healthit.gov/sites/default/files/norc_beaconevalcharacterizingcommunities_march_2013.pdf.

Table 1. Lead Organization, Approach to Exchange Infrastructure Development, and Means of Data Sharing, by Community

| Beacon Community | Lead Organization | Type of Lead Organization | Approach to Infrastructure Development | Health Information Infrastructure used by Beacon | Availability of Exchange Mechanisms in each State* |
|---------------------|----------------------------------------------------|---------------------------------|----------------------------------------|--------------------------------------------------|----------------------------------------------------|
| Bangor | Eastern Maine Health System | Integrated Delivery Network | Strengthen | Statewide | Query-based & directed |
| Central Indiana | Indiana Health Information Exchange, Inc. (IHIE) | Health Information Organization | Strengthen | Regional | Query-based & directed |
| Colorado | Rocky Mountain Health Plan | 501(c)3 Community Organization | Strengthen | Regional | Query-based & directed |
| Crescent City | Louisiana Public Health Institute (LPHI) | 501(c)3 Community Organization | Build | Regional | Query-based & directed |
| Delta BLUES | Delta Health Alliance (DHA) | 501(c)3 Community Organization | Build | Statewide | Query-based & directed |
| Greater Cincinnati | HealthBridge | Health Information Organization | Strengthen | Regional | Query-based & directed |
| Hawai'i | University of Hawai'i at Hilo, College of Pharmacy | Academic Institution | Build | Regional | Directed |
| Inland Northwest | Inland Northwest Health Services | 501(c)3 Community Organization | Strengthen | Regional | Query-based & directed |
| Keystone | Geisinger Health System | Integrated Delivery Network | Strengthen | Regional | Query-based & directed |
| Rhode Island | Rhode Island Quality Institute (RIQI) | 501(c)3 Community Organization | Strengthen | Statewide | Query-based & directed |
| San Diego | U.C. San Diego | Academic Institution | Build | Regional | Query-based & directed |
| Southeast Michigan | Southeastern Michigan Health Association (SEMHA) | 501(c)3 Community Organization | Build | Regional | Query-based & directed |
| Southeast Minnesota | Mayo Clinic | Integrated Delivery Network | Build | Regional | Query-based & directed |
| Southern Piedmont | Community Care of Southern Piedmont | 501(c)3 Community Organization | Strengthen | Regional | Query-based & directed |
| Utah | HealthInsight | 501(c)3 Community Organization | Strengthen | Statewide | Query-based & directed |
| Tulsa | MyHealth Access Network | 501(c)3 Community Organization | Build | Regional | Query-based & directed |
| Western New York | HEALTHeLINK | Health Information Organization | Strengthen | Regional | Query-based & directed |

*Shows the availability of exchange mechanisms in each state as of Q3 2013. Query-based, or “pull”, exchange refers to the ability for providers to find or request information on a patient from other providers. Directed, or “push”, exchange refers to the ability to secure sent and receive information electronically between providers. Source: <http://www.healthit.gov/policy-researchers-implementers/state-hie-implementation-status>

Methods

To gather information about how the Beacon Communities were developing or enhancing health IT and measurement infrastructure to support clinical transformation, NORC conducted seven site visits between November 2012 and March 2013. NORC, in consultation with ONC, selected these seven Communities to represent diverse program features, including the type(s) of health IT being implemented; the size, composition, and scope of the target patient and provider populations; degree of sophistication of the health information exchange/health IT infrastructure prior to the Beacon award; the scope and nature of the challenges encountered as part of building and strengthening activities; and participation in other health IT programs or initiatives. As part of the site visits, NORC conducted semi-structured discussions with a range of stakeholders in the Communities, including:

- Beacon Community leadership committees and program staff;
- state (HIE) designated entity Directors and staff;
- Regional Extension Center (REC) representatives;
- state public health officials;
- care managers and care coordinators;
- large health systems and ambulatory care providers;
- managers and practitioners in federally qualified health centers and community health centers;
- community partners;
- representatives from health plans; and
- local Beacon evaluators.

In addition, from August through October 2013, NORC held a series of semi-structured 60-minute discussions with the remaining 10 Communities. These calls included a range of Beacon Community members, including the project director, project manager, evaluation director, IT manager, and other individuals who could provide insight into the Beacon Community implementation experience.

Following each site visit or discussion, NORC summarized the information gathered, including interview transcripts, team observations, and other documents provided by the Community to facilitate a within-Community analysis of context and stakeholders, intervention strategies, enabling factors, and challenges to progress. NORC then analyzed these data to identify both common and unique factors across the Communities.

Key Findings

In the sections below, we present key findings on Beacon Community experiences with building and strengthening infrastructure for electronic exchange of health information. Specifically, we address factors affecting the establishment of health information exchange, strategies to enable exchange, and insights for future community collaborations.

Factors Affecting the Establishment of Exchange Infrastructure

Contextual factors shaped the ease with which Communities established systems for health information exchange, as well as the strategies they used to do so. These factors included where each Community stood at baseline with respect to its existing technology infrastructure; local health care market dynamics; and the legal and policy environment in each Community. In this section, we address each in turn, highlighting examples from across the 17 Communities.

Baseline Infrastructure and Technical Issues

Developing effective health information exchange can be both time-consuming and resource-intensive, and existing infrastructure and functional capabilities can affect Communities' ability to meet health information needs and goals. Some Communities experienced delays in implementing their Beacon program initiatives, as they first had to resolve issues around interoperability, inadequate technological solutions, and the resources committed to other IT-related endeavors under way at the time.

While Beacon Communities had higher-than-average levels of EHR adoption, the lack of interoperability in early EHR systems complicated information exchange. Many providers in Beacon communities were early adopters of EHRs. Interoperability was not a primary feature of early-stage EHR systems; in fact, many providers at this time had custom-built systems. Many communities with high levels of EHR adoption had a number of different systems in use that were not interoperable. Inland Northwest, for example, had high levels of EHR adoption prior to receiving Beacon funding. As of the last quarter of 2010, 64% of ambulatory providers in the Community's catchment area—that is the bounded geographic region within which the Community offered services and recruited providers—had adopted an EHR, above the national average EHR adoption rate of 47%.² For Inland Northwest to facilitate exchange, this Beacon had to make the legacy EHR systems of nearly two-thirds of their providers interoperable with their central care management data system. Similarly, high pre-Beacon EHR adoption rates—64% as of the last quarter of 2010³—in the Salt Lake City area meant that a wide array of EHRs were already in use; rarely did more than five private practices use the same type of EHR. As a result, connecting providers to a common clinical health information exchange system required intensive support from the Beacon program, providing tailored solutions to nearly every practice. In the Southeast Michigan Beacon Community, institutions purchased products that facilitated internal information exchange with affiliated providers, leading to many systems with their own internal data hubs—connecting multiple EHRs for data exchange. This complicated the process of achieving community-wide data exchange.

Unexpected limitations in EHR vendor capability often slowed the progress of Beacon Communities in developing the right technology solutions. Some Communities reported that various health IT “out of

² NORC at the University of Chicago. (2013). *Characterizing the Beacon Communities*. Washington, DC: Office of the National Coordinator for Health Information Technology (ONC). Retrieved from http://www.healthit.gov/sites/default/files/norc_beaconevalcharacterizingcommunities_march_2013.pdf.

³ Ibid.

the box” products were unable to meet their needs so they often had to work with vendors to develop solutions that allowed them to achieve their intended goals, a process that delayed the progress of some interventions. For example, the Greater Cincinnati Beacon encountered various EHRs that in practice could not produce the data needed to meet Meaningful Use requirements. Additionally, they underestimated the level of effort needed to extract data from EHR systems to populate a disease registry while overestimating the quality of EHR data. The Beacon also spent more money than planned on paying contractors to build the technology solutions, enhancing the registry, extracting data from their health IT system, and normalizing the data. While the Greater Cincinnati Beacon noted that the design was ultimately successful and scalable, the process of building an Emergency Department/Admission Alert System aimed at reducing preventable ED visits and readmissions in their existing exchange infrastructure took longer than expected.

Similarly, the Greater Tulsa Health Access Network Beacon Community noted the EHR vendors were not as sophisticated as expected. Setting up the exchange platforms took seven to eight months longer than anticipated. Additionally, Tulsa noted the continuity-of-care documents (CCDs) the vendors produced did not have the functionality that the Beacon had expected. Thus, the Beacon shifted to a policy of selecting the “best of breed,” working with new vendors as needed, noting that being too dependent on any single vendor is a “path to failure.” Ultimately, Tulsa believes being a health organization that supports multiple technologies is critical for success. The Western New York Beacon reported being overly optimistic about the capabilities of their software in their existing environment; they ultimately had to delay rolling out a new exchange functionality that would update medication histories in EHRs when diabetic patients have been seen in the emergency department or discharged from a hospital or long-term care facility.

Sometimes limitations in vendor capabilities to meet Meaningful Use requirements challenged Beacon Communities in that providers were understandably focused on upgrading or replacing their EHR systems, rather than interfacing with Beacon systems. San Diego, Hawai’i Island, and Western New York Beacon Communities, among others, reported limitations with their initial systems for electronic health information exchange and delays resulted from switching vendors.

Information exchange with smaller ambulatory and independent providers was a challenge for many Beacons. Smaller practices that were not part of larger health systems often lacked sufficient infrastructure and administrative bandwidth to assume additional tasks related to data exchange. For example, the Hawai’i Island Beacon Community found that small practices in their region did not have the time to build interfaces into local health information exchange systems. As such, the Hawai’i Island Beacon spent more time than expected grappling with developing interfaces and technical aspects of the initial assessment as well as actually getting the information needed to connect and testing it to ensure it was operating adequately. Understanding the limited administrative bandwidth and basic infrastructure of many smaller practices is an important lesson for regions with many independent practices that are not part of large health systems.

The Rhode Island Beacon Community noted that many independent primary care practices had little previous experience with executing data use agreements, participation contracts, and business associate agreements, which increased the time and cost of onboarding these practices to the health information exchange. In order to engage these providers, the Beacon, led by the Rhode Island Quality Institute (RIQI), incurred the legal costs of modifying these agreements to accommodate a variety of practices. In addition, practices had to comply with Health Insurance Portability and Accountability Act (HIPAA) requirements to participate in the program. When executing data use agreements, the Beacon found that a number of practices had insufficient privacy and security practices in place and little experience with electronic data exchange. The REC (also administered by RIQI) developed education and best practices for privacy and security that has been used statewide.

Providers had difficulty focusing on meeting Beacon intervention requirements in light of other initiatives that were sometimes competing, sometimes synergistic. Due to new financial and service delivery arrangements stemming from the Affordable Care Act and various parallel funding initiatives—including the State HIE Cooperative Agreement program, REC program, Meaningful Use incentive payments, accountable care organizations, and patient-centered medical homes—large health systems often had to focus on handling regulation and reimbursement changes, rather than on the implementation of Beacon interventions. For example, the Southeast Michigan Beacon reported that Meaningful Use was both helpful and disruptive, noting that Stage 1 Meaningful Use requirements did not specifically recognize and reward community-based data exchange. Thus, in the short term, health systems prioritized activities such as implementing a new information system to meet Meaningful Use standards rather than those to achieve community data sharing. At the same time, Meaningful Use did increase the number of providers with EHRs who could ultimately participate in health information exchange.

Health Care Market Dynamics

The structure of the local and state health care marketplace was a critical factor in the way Communities implemented their Beacon interventions and their ability to establish data-sharing infrastructure for clinical transformation. For some Beacon Communities, policy and business changes in the local health care marketplace created new challenges; in others, community providers readily embraced efforts by the Beacon collaborative to support data sharing among organizations.

Level of market competition within a Community played an important role in providers' willingness to engage in data sharing activities. Beacon Communities operating in highly competitive environments faced resistance from health systems in sharing data with other systems, as they viewed their utilization and patient records data as a commercial asset.^{4,5} The Southeast Michigan Beacon, for example, had one of the least concentrated and most competitive markets among the Beacons,⁶ with six or seven very large health systems and some smaller hospitals—about 40 hospitals in total. Leadership of the Southeast Michigan Beacon reported difficulty engaging local systems in data sharing as many providers viewed data as a competitive asset, believing that retaining control of their data was necessary for retaining their patients and share of the market.

For the Beacon Community of the Inland Northwest, the entrance of a national health group into the local market introduced new dynamics into a historically collaborative relationship among local hospital systems. At about the same time as Beacon initiatives were getting underway, a for-profit chain that was not interested in participating in a community data repository acquired one of the two major nonprofit hospitals in the city that had initially been a Beacon partner. As formerly independent community practices began to align themselves with one or the other of the major hospital systems, they became less amenable or able to participate in the Beacon. Hospitals became more focused on internal data-sharing capabilities and capacity-building, proprietary interests, and developing accountable care organizations (ACOs).⁷ As a result of these new market dynamics, the Inland Northwest Beacon revised its plans for recruiting practices in the Spokane metropolitan area and focused instead on rural clinics and federally qualified health centers across a wider region.

In contrast, for other Communities the local health care market environment enabled data sharing and connectivity. For example, Maine has one of the lowest population densities and least competitive health

⁴ See also Adler-Milstein J, DesRoches CM, and Jha AK, “Health information exchange among American hospitals,” in *Am J Man Care* 17 (11), 761-8, 2011.

⁵ See also http://www.healthit.gov/sites/default/files/casestudysynthesisdocument_2-8-13.pdf.

⁶ NORC, 13.

⁷ For additional contextual information on Washington State's HIE experience, see http://www.healthit.gov/sites/default/files/wa_casestudyreport_final.pdf

care markets⁸ of all the Beacons—primarily due to the geographic dispersion and modest size of the state’s provider community. As a result, the Bangor Beacon Community’s health systems were predisposed to work with each other and share information.⁹

Crescent City focused its Beacon efforts on an existing network of primary care clinics with established data-sharing relationships. Prior to Hurricane Katrina, the Crescent City Beacon Community’s health care market was highly segmented. After the hurricane, Louisiana received a \$100 million Primary Care Access Stabilization Grant (PCASG) to create a network of community clinics to replace two large public hospitals that were damaged by the storm.¹⁰ Prior to Beacon, this network and the Interim Louisiana State University (LSU) Public Hospital shared patient data through an in-house legacy system connected to the LSU network. This primary care network, which was already collaborating and exchanging data in Greater New Orleans, had the infrastructure and relationships to facilitate collaboration for Beacon.

The presence of a large health plan or integrated delivery system in the Beacon Community influenced the design of data sharing infrastructure. Several Beacons operated within an area that had a dominant health plan or integrated delivery system that was able to capitalize on its IT infrastructure and expertise to advance health information exchange throughout the community. Geisinger Health System, an integrated health services organization widely recognized for its EHR use, led the Keystone Beacon Community in Pennsylvania. Geisinger has 42 clinics, a major medical center, smaller community hospitals with 1.5 to 2 million visits per year, as well as a health plan. Care management and communication between providers existed within the organization prior to Beacon; this approach was validated as a model within the system and then introduced and piloted in independent clinics. For the Beacon project, Geisinger successfully forged partnerships with non-Geisinger community hospitals to share their data. Data from these other hospitals were pulled into a community data warehouse constructed by Geisinger, but maintained as a freestanding repository, with firewalls between the Geisinger system and the Keystone data warehouse.

Similarly, the San Diego Beacon Community reported that the Kaiser Foundation Health Plan, one of the biggest commercial insurance providers in San Diego County, was engaged in the Beacon effort. As an entity of Kaiser Permanente, the managed care consortium, Kaiser’s health plan enrollees comprised a large majority of Kaiser’s hospital (San Diego Medical Center) patient base. However, Kaiser Permanente owns only one hospital in the San Diego region and outsources a significant volume of services to other hospitals.¹¹ Kaiser saw the Beacon initiative to connect providers across the community as a model for Kaiser’s community connections. Kaiser’s sophistication and experience with data exchange has benefitted the San Diego Beacon by providing access to advice on policies and data management and facilitating interactions with other data partners.

Likewise, the Southeast Minnesota Beacon Community builds on Mayo Clinic’s 50-year history with the Rochester Epidemiology Project, a long-standing collaboration of health care providers who share medical records to study the causes and outcomes of different diseases in southeast Minnesota.¹² The mechanics of data transfer were built off of the Rochester Epidemiology Study, so no one provider had a claim to the data. The Southeast Minnesota Beacon was able to use staff who were already in place, who inspired confidence and trust in the Beacon initiative that an entirely new operation would not have been able to muster. The Beacon credits this history of joint endeavor with enabling the Beacon to get off the ground.

⁸ Ibid.

⁹ For a case study of Maine’s HIE environment, see http://www.healthit.gov/sites/default/files/me_casestudyreportfinal.pdf.

¹⁰ For more information on the PCASG funding, see the 2009 GAO report, available at <http://www.gao.gov/products/GAO-09-588>.

¹¹ For more information, see *San Diego: Health Care Providers Expand Capacity as Competition Increases for Well-Insured Patients*, available at: <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/A/PDF%20AlmanacRegMktBriefSanDiego13.pdf>.

¹² For more information on the Rochester Epidemiology Study, see <http://www.rochesterproject.org/>.

Other Communities, however, could not rely on a large health system or integrated delivery network to provide a foundation on which to expand data-sharing infrastructure and systems to the broader provider community. These large systems cited proprietary interests and concerns about data quality as reasons for not participating in data exchange outside of their organization. For example, the Utah Beacon Community cited a partner’s reluctance to engage in clinical data exchange. This partner had a robust internal health information exchange system but expressed concern about compromising their internal system’s data quality if they were to introduce externally produced data into their own system.

Legal and Policy Issues

The state and local policy landscape for information exchange is complex and can have a big effect on what information exchange looks like and the strategies needed to drive adoption. In particular, acquiring patient authorization and consent for retrieving data from repositories, as well as federal and state policies governing information about behavioral and mental health services, can lead to limited data being available in repositories and retrievable by other providers. In this section, we describe how laws and policies governing patient consent, protection of sensitive data, and privacy and security influenced Communities’ approaches to establishing infrastructure for exchange.

Consent policies for exchanging health data created challenges for some Beacon Communities.

Patients’ consent for providers to share their health information with other providers may occur either on an “opt-in” or “opt-out” basis. Opt-in requires that a patient actively agree, usually in writing, that their information may be shared by their provider with others. “Opt-out” presumes a patient agrees for their health information to be shared with other providers unless they explicitly state that they do not agree to such sharing. State laws often govern a state’s consent model. Beacons in “opt-in” states often experienced challenges collecting patient data and acquiring a critical mass of data in their exchange systems and clinical data repositories. Some Communities with opt-in consent policies noted the collection of patient consent was slow and time-consuming, though they often developed solutions to collecting patient consent or deployed trainers to engage and inform patients about the importance of data sharing.

In Utah, when the statutory basis for patient consent for the Clinical Health Information Exchange (cHIE) system changed from an opt-out to an opt-in policy, patients had to sign a (paper) consent form specifying who is permitted to view their data in the clinical repository. Many of these forms had to be manually entered into the system, which was time-consuming. Utah Beacon staff devoted a significant amount of time to supporting practices to collect patient consent. Due to the shift in consent models, limited data were initially available through cHIE.

Communities with opt-in consent models developed solutions to engage patients in data sharing:

- Crescent City Beacon Community developed a uniform patient consent form to be administered by clinics that follows the patient around the community to allow their data to be shared with the Greater New Orleans HIE (GNOHIE), the infrastructure Crescent City used for health information exchange.
- In the Western New York Beacon’s information exchange organization, HEALTHeLINK, a patient’s consent applies to everyone working with the patient; as such, it is not necessary to acquire consent for every provider the patient works with. Additionally, Western NY employed nurse trainers who trained people on how to get consent in emergency departments, leading to improvement in EHR access in hospitals as well.

Across the Communities, Beacon leadership emphasized the importance of patient engagement around consent and data sharing. The Southeast Michigan Beacon Community developed materials for practices to distribute to patients about sharing their health information and their right to opt-out. By stressing the importance of getting the right information to providers at the right time with electronic exchange, the

Southeast Michigan Beacon found that people were very willing to participate and frequently assumed this exchange had been—or should have been—occurring all along.

State requirements intended to protect sensitive health information presented similar challenges to acquiring a critical mass of complete patient data in repositories and the sharing of those data.

Federal law (42 CFR Part 2) protects the information of any patient in a substance abuse education, treatment, or prevention program that is conducted or assisted by the federal government. States laws may mirror or exceed these regulations. While these laws are intended to protect confidentiality, they can present obstacles to seamless data sharing and can limit the completeness and usefulness of data. In Pennsylvania, state policy protects sensitive health information—information regarding HIV, psychotherapy, and substance abuse. In order for patients to authorize their data to be submitted to the Keystone Beacon’s health information exchange system, KeyHIE, patients had to sign a form with each organization allowing them to share information with other providers; one patient may have to sign up to ten authorization forms. Similarly, Bangor Beacon Community found that federal law prevented the sharing of clinical information originating with substance abuse treatment providers. For providers integrating substance abuse treatment with mental health or other clinical care, it is difficult to disentangle protected substance abuse information from non-protected information within the EHR. Similar to protected behavioral health information, the Western New York Beacon Community noted that New York State privacy policies protecting health information in cases when a minor provided consent for their own care resulted in a gap in data.¹³ Southeast Michigan Beacon Community established a Privacy and Security Workgroup, developing privacy protocols and procedures to make sure the information exchange system would be viewed as a trusted entity and that patient information is protected. The workgroup, which consisted of experts from stakeholder organizations including legal experts and clinician representatives, reached consensus on many data sharing agreements. Though the process took up to nine months, having legal affairs experts on the team sped up the process because they confirmed the legal soundness of the plan and approach before circulating the agreements among providers.

Negotiating necessary legal agreements and meeting administrative requirements proved to be more time consuming than Beacon Communities anticipated. Beacons sponsored by universities, or with universities as partners, acknowledged that meeting internal university processes for the Beacon awards, such as gaining Institutional Review Board (IRB) approval for their interventions and data collection, took more time than had been scheduled for these preliminary steps in implementation. Unanticipated delays in negotiating legal agreements for connectivity were also a common occurrence among Beacons. In New Orleans, the Crescent City Beacon Community reported that connecting providers to the community data exchange system, Greater New Orleans HIE (GNOHIE), took longer than expected partly due to delays in completion of data sharing agreements. Greater Cincinnati reported that they were optimistic in forecasting the timeline for completing data use agreements (DUAs), which ultimately took 10 months—much longer than expected. The Southern Piedmont Beacon Community noted that negotiating DUAs with major health care systems in the catchment area was a much more time-consuming and challenging process than had been anticipated as local integrated delivery systems initially resisted signing DUAs due to serious concerns about sharing data with their competitors. In other cases, such as in Rhode Island, the Beacon found itself assisting small provider organizations with little experience drafting DUAs.

¹³ For more information, see *Barriers to the Exchange of Pediatric Health Information*, available at: http://nyhealth.org/wp-content/uploads/2012/05/Barrier-to-Exchange_pediatric_white-paper_2010.pdf.

Strategies Enabling Health Information Exchange

Despite the aforementioned challenges, Beacon Communities also reported various factors that enabled them to establish the necessary infrastructure and connectivity for data sharing.

Leveraging previous collaborations and relationships eased obtaining buy-in from stakeholders to exchange information and develop infrastructure. Most Communities noted governance structures, infrastructure, and relationships established through previous collaborative efforts facilitated buy-in from key stakeholders to achieve connectivity. Bangor Beacon Community interviewees, for example, repeatedly cited the history of collaboration, at both the local and state levels, as a key enabler in its success. Executives from the three leading organizations—Eastern Maine Healthcare System, Penobscot Community Health Center, and St. Joseph Hospital—convened and shared successes and challenges on a regular basis since the project commenced. While the Beacon partners had cooperated in the past, the Beacon award gave them a significant focus and mechanism for explicit collaboration.

Western New York Beacon Community had established partnerships and a governance structure for its regional HIO, HEALTHeLINK, prior to receiving Beacon funding. HEALTHeLINK’s board is comprised of senior executives and chief executive officers of the largest health systems in the area—made up of the four largest hospitals in the area—and a cancer research institute. In addition, the board includes three payers that collectively cover approximately 80% of the individuals in the Western New York community not covered by Medicaid or Medicare. Western New York noted this history and existence of a governance infrastructure strongly positioned HEALTHeLINK for the Beacon interventions.

Other examples of Beacon Communities leveraging previous collaborations:

- In Greater Cincinnati, a number of quality improvement (QI) initiatives and partners predated Beacon. For Cincinnati Beacon’s asthma QI improvement group, a set of 39 practices were already involved. Likewise, Cincinnati Children’s Hospital also had some pre-existing QI groups. Though these groups needed to be engaged, they were automatically part of the Beacon and ramped-up very quickly.
- The Delta BLUES Beacon Community had existing staff working on EHR implementation prior to the program, including clinical nurses and a physician, and a core support group monitoring usage and adding users. They also had outreach personnel who would go to the clinics and monitor utilization.
- Tulsa began a community-wide QI initiative about six months before the Beacon solicitation was released. In the summer of 2009, the Mayor pulled together a coalition of health care leaders from across the community at a town hall meeting as an open forum for all executive leadership from various health care stakeholders in the region to consider the quality of care in the region.
- Indiana demonstrated the benefits of longstanding relationships involving multiple stakeholders. Indiana has been very transparent with how data are used, where they are used, who can access them, and the mechanisms used to look at them. Physicians and patients are very clear on how data are used and how data-use cases are vetted and agreed upon. There is also a clear process for disengaging and removing data from the system so that, if an organization chooses to disengage and pull their data, the process is available and well understood.

Leveraging previously developed IT infrastructure and expertise helped Communities establish data sharing infrastructure. Communities with experiences on similar initiatives or who built their Beacon initiatives upon previously existing infrastructure were able to advance their initiatives and facilitate the further development of health IT. For example, Maine’s data sharing system (HealthInfoNet) was well developed at the start of Beacon; all providers participating in the Bangor Beacon Community were connected to HealthInfoNet. Similarly, Inland Northwest Health Services (INHS), the lead organization of the Beacon Community of the Inland Northwest, oversaw a health information management system and other shared services for regional health systems prior to Beacon. It had extensive health IT expertise and resources for hosting software, creating interfaces with external

systems, training programmers, conducting data mapping, and understanding architecture. INHS applied this experience to the Beacon program by housing, implementing and maintaining clinical decision support tools for population health management and supporting Beacon providers in their use.

In addition, Mayo Clinic, the managing partner in the Southeast Minnesota Beacon Community, had an established and experienced IT department and used the same technologies on a national consortia project, the Care Connectivity Consortium, which served as a pilot for Beacon services and operational structure. The Southeast Minnesota Beacon acknowledged that without Mayo's IT support, establishing the Beacon community and services would have been difficult. The Beacon program was designed to support multiple platforms and to allow groups transitioning EHR systems to continue without problems. Some Communities were able to take advantage of their pre-existing health IT capabilities and expertise to spread the intervention beyond Beacon practices.

Communities worked with policymakers and other stakeholders to ensure data sharing was not restricted while still protecting health information. Although California has an opt-in consent policy, as a pilot program the San Diego Beacon obtained a waiver from the state to allow health care providers and systems to decide their preferred approach, either opt-in or opt-out. The various partners established different policies. Although this approach proved challenging, San Diego Beacon leadership noted that a uniform (i.e., non-distributive) consent model could also be problematic in working with diverse systems and providers, and that the distributive consent model allows partners to feel comfortable because they could elect their preferred approach. Other Communities proactively worked with state legislative bodies to ensure that as policies were implemented, strict regulations were not placed on health information exchange systems. The Greater Cincinnati Beacon operates in three states with similar privacy and security requirements—Ohio, Kentucky, and Indiana. At one point, however, Greater Cincinnati faced the prospect of a new, restrictive consent policy in Ohio. The Greater Cincinnati Beacon worked with the state to help craft language that avoided a strong requirement to have patient consent for any kind of data exchange.

In order to engage smaller practices in data sharing, Beacon Communities sometimes had to work with larger health systems, hospitals and physician organizations. Some Communities noted that the trend of small and ambulatory providers joining larger health systems facilitated engaging these practices in data sharing. Practices affiliated with large hospital systems could often use the resources and expertise of these systems to enable connectivity, often via internal networks. In Bangor Beacon Community, hospital ownership of physician practices facilitated the incorporation of most ambulatory care clinics in Bangor into Beacon interventions. Bangor's Beacon encompassed all health care systems, secondary and tertiary hospitals and emergency departments, federally-qualified health centers, and about two-thirds of primary care physicians in the Bangor area. One implication of this arrangement was that primary care physicians had support from a hospital or health system IT department, which allowed for rapid adaptations of provider EHRs to conform to the requirements of the Beacon-related intervention. While most physician practices in Bangor had EHRs in place prior to Beacon, Bangor Beacon's leadership was able to move all of the practices in the community to a common EHR, which also facilitated customizing the EHR to meet Beacon programmatic requirements such as clinical performance measurement.

Similarly, in Southeast Michigan, many providers are independent and physician organizations provide them with an integrated business infrastructure; over 100 physician organizations exist across the state, including roughly a dozen within the Southeast Michigan Beacon catchment area. Thus, Southeast Michigan had to engage with these organizations in order reach small practice providers. Some practitioners' only affiliation with hospitals was for IT services and some of the physician organizations were controlled by hospitals. In this case, the Southeast Michigan Beacon would need to seek permission from large hospital systems in order to connect the small practices.

Key Lessons for the Future

Communities that are just beginning efforts to share and exchange clinical health information can draw on the Beacon Communities' experience over the past three years. The following includes insights offered by the Beacons themselves as well as summary findings from the evaluation.

The ability to directly manage and configure IT systems allows organizations to more quickly and efficiently meet provider needs. Communities that host their own health IT infrastructure, as opposed to relying on off-the-shelf products or contracted services, customized their IT tools to improve the ease of use of systems. Crescent City Beacon's open source solution for the Greater New Orleans Health Information Exchange (GNOHIE) system—Mirth—allows the Louisiana Public Health Institute to create, manage, and control the technology infrastructure internally, enhancing workforce and organizational and community capacity. Crescent City Beacon also provided the resources to pursue answers and solutions beyond those that other software system vendors offer. For example, the Louisiana Public Health Institute used their health IT expertise in interfacing with vendors to develop solutions for other providers who wanted to connect to GNOHIE.

Additionally, health IT infrastructure directed at the community-level allowed Beacons to respond more quickly to any needed changes to systems that would facilitate workflow or ease of use for data sharing. As lead organizations in their respective Beacon Communities, Geisinger Health System, Eastern Maine Healthcare System, and the Mayo Clinic had internal IT staff who were able to address software issues faced by community-based practices within relatively short time periods because of the resources they could bring to bear on problems. The Utah Beacon Community noted that providing sufficient IT support can lead to innovative solutions, whereas relying on “out-of-the-box” EHR software does not. Often, as both the Utah and Colorado Beacons pointed out, providers have already purchased all of the software they need but are unaware of its functionalities and need someone to teach them how to use their system.

The Southeast Minnesota Beacon Community has an EHR and reporting system in the public domain (PHDoc), which started in 1986. Local public agencies in Minnesota co-own the product. This allowed the Beacon to contract with an outside vendor, Xerox, while retaining the same staff. Because local public health departments own and control the product, they decide how much they are going to spend, enabling them to expand its use to 11 counties in Minnesota; three counties that had not been part of the system agreed to switch over. One lead among the public agencies was voted to be the project manager for PHDoc and Beacon, giving the co-owners a level of autonomy that allowed the Beacon to accomplish a lot. Southeast Minnesota leadership concluded that working with an outside vendor would have slowed progress because every decision would have had to be negotiated. Prior to Beacon, the degree of interoperability among counties was somewhat limited; Beacon enhanced the interoperability among counties.

The involvement of influential stakeholders in leadership positions helps garner buy-in from providers and the community for establishing health information exchange infrastructure. Strong leadership is essential for influencing policy and maintaining a clear vision throughout the establishment of data-sharing infrastructure. Many Communities mentioned physician leadership to champion the Beacon innovations as a necessary element for success. Bangor Beacon Community is notable for the degree of engagement of community physicians in constructing the Community's performance measures, selecting from or modifying endorsed measures in a spirit of inquiry and collective judgment.

Perceived neutrality of and commitment to community-wide care improvement by the organization managing community data is necessary for fostering trust among providers and consumers. Some Beacon Communities established or benefitted from the presence of a neutral convener to establish trust and garner buy-in from key community stakeholders on the importance of data sharing to achieve clinical transformation. For example, the Tulsa created a neutral organization that would develop a common IT

infrastructure to help all hospitals and practices provide better care to the community—the MyHealth Access Network. Tulsa involved payers to establish buy-in for the concept of establishing a neutral third party to measure performance, MyHealth offers a single location where all stakeholders could contribute data and access results and MyHealth could assess community activity related to exchange and measure progress toward community goals.

In Utah, the quality improvement organization, HealthInsight, had historically served as a neutral convener and credible resource to providers in the Salt Lake community. Also Utah’s REC, HealthInsight has strong relationships with many of the clinics around health IT. It used these relationships to recruit clinics to participate in data exchange and serve as a trusted source of assistance to participating providers. In the Keystone Beacon Community, non-Geisinger hospitals engaging in health information exchange entrusted the Beacon to house their data in a community data warehouse, separate from Geisinger data; only the Keystone Beacon has access to these data. KeyHIE, Keystone’s community-wide data sharing system, provides patient identifiers via a master patient index to link data from separate tools (e.g., community data warehouse, the Beacon analytic and database system [Wisdom]). Similarly, the San Diego Beacon noted that innovation and health information exchange systems have to be built on neutral ground; thus the Beacon’s HIE infrastructure was ultimately constituted as an independent community entity.

It is important to note, however, that while a neutral organization can convene disparate parties, it may lack the clout and in-house resources that a large health system can bring to a collaborative endeavor and inspire confidence in its sustainability.

Communities looking to establish a shared health IT infrastructure or implement clinical transformation initiatives using health IT should build in enough time, as the process of laying the groundwork for automated performance measures, reporting, and data exchange involves many steps and is resource-intensive. Several Beacons underestimated the lead time needed to prepare for clinical data exchange and practice-based performance measurement. They noted that building enough time to allow for the delays in establishing infrastructure, developing necessary business use agreements or other documents needed to formalize connections, and acquiring trust and buy-in from the community are needed to achieve results.

The Beacon Community of the Inland Northwest noted that establishing infrastructure for exchange and recruiting partners, especially independent practices lacking support from hospitals or health systems, required one-on-one negotiations and technical support. Targeting distant rural communities and systems such as the Indian Health Service required extra effort and time but also addressed areas with great need and opportunities to benefit from clinical health information exchange and practice support. The Utah Beacon Community in Salt Lake, the Tulsa Beacon, Rhode Island Beacon, and Greater Cincinnati Beacon all found that health IT efforts, whether aimed at EHR-based performance measurement and provider feedback or at establishing data exchange, required greater technical support from Beacon or REC staff than initially planned. The multiplicity of EHR systems within most of the Beacon Communities required customized interfaces between community providers and the health information exchange system or data repository. Often, the resources of a dominant health system or REC support helped with IT training and interfacing at community-based practices for performance reporting and data exchanging, as discussed below.

Community involvement in decision-making, although requiring an investment of time and staff resources, solidifies support for sustainable health information exchange organizations and activities over time. Community involvement in the process of developing GNOHIE in the Crescent City Beacon lengthened the decision-making process. Community members have, however, bought into these initiatives. GNOHIE provides value-added services that meet provider needs and are integrated into clinic

workflow—for example, notification of emergency department visits or hospital admissions—improving its sustainability. SE Minnesota also undertook extensive community consultations and engagement to ensure consumer support for and confidence in the security and value of health information exchange. Although the stakeholder engagement process is often time consuming, without this key step infrastructure developed may not serve the needs of the community and may ultimately not be utilized.

Build in flexibility to help practices at all levels of readiness, including smaller practices that may have less sophisticated health IT infrastructure than large hospital systems. Communities quickly learned that their ability to connect smaller practices to their exchange infrastructure often required more one-on-one assistance, as these practices often lacked resources or staff to maintain their EHR infrastructure. For example, the Rhode Island Beacon Community was careful not to assume that all provider organizations were equipped to begin improvement work, as they found there was a lower level of readiness than expected and more work had to be done than originally thought. Many independent practices required support for basic business and administrative functions, as well privacy and security training to be compliant with the Health Insurance Portability and Accountability Act (HIPAA). The Beacon team also found that many practices had no prior experience with performance improvement processes, such as Plan-Do-Study-Act (PDSA), performance measurement and monitoring. The Greater Cincinnati Beacon noted that in order to support practices in the quality improvement (QI) work at the heart of their Beacon interventions, the collaborative itself had to acquire new skills. Only well into the program were they able to teach providers how to use these IT tools to transform their practices. Ultimately, incorporating the tools within QI was one of the Beacon’s biggest successes.

Offering services that supplement rather than replace existing systems add value for providers that participate in data sharing. The San Diego Beacon recommended being strategic about the kind of services offered. Many institutions already have their own programs and services, so a community collaborative must identify value-added services internal systems cannot provide. These include information exchange and applications for achieving Meaningful Use. While San Diego initially had many applications to offer, they assessed health systems’ existing capabilities and elected to leverage the Community’s connections with cardiologists from three major providers to develop a “super clinic” that would allow any provider to access data at the point of care.

The Tulsa Beacon, with the MyHealth Access Network and its health data repository, created a valued analytic capacity available to payers and providers that can produce community-level reports on utilization measures such as 30-day readmissions by readmitting facility and emergency department utilization by facility. The MyHealth Access Network also notifies providers about patients in their panel who need screening or monitoring testing for a specific chronic condition, and can identify high-frequency users of emergency department services within their practice population.

The Greater Cincinnati’s successful emergency department alert initiative provided real-time notifications to primary care practices when their patients with diabetes or asthma had an emergency department or inpatient episode. Greater Cincinnati found that a high degree of coordination with partners and providers was needed to identify services that added value for providers—such as the alerts—and achieved success only once the partner organizations’ value propositions and goals were aligned and merged. The real-time alerts service complemented the Beacon partners’ existing efforts and supported their achievement of Meaningful Use and Patient-Centered Medical Home designations.

Another example from this Beacon Community also brings home the same point. When Greater Cincinnati established a registry for children with asthma at the Cincinnati Children’s Hospital, the Beacon did not initially engage and train provider practices—so providers did not use it. After forming a QI performance solutions team to enlist clinicians’ use of the registry’s data at the point of care, they increased clinicians’ engagement.

Integrating data sharing capabilities into providers' EHR systems promotes use of the data sharing systems because it is more efficient for providers. Multiple portals and logins to access the EHR and HIE systems can create provider frustration as additional logins and extra clicks detract from a provider's workflow. A feature of significant value to participating providers is a single point of access to the health information exchange system or clinical data repository from within practices' EHRs. Both the Tulsa and Bangor Beacon noted that this created efficiencies at the point of care.

Provider readiness assessment and defining the incremental steps preparatory to data sharing promote provider engagement and success. The Keystone Beacon developed an assessment tool that enabled them to work with practices to determine their baseline activities and potential for connectivity. Through this mechanism, Keystone was able to tailor interventions to individual practices and determine which ones were ready to establish connections with KeyHIE. Similarly, the Rhode Island Beacon established specific activities to take a provider through the process of adopting health information exchange services, such as provider portals, hospital alerts, and Direct secure email. In addition, the Rhode Island Beacon, which also served as the REC, used Salesforce, a customer relationship management system, to support formal adoption processes for interested participants and enrolled providers.

In addition to its technological tools, the Rhode Island Beacon relied on "relationship managers," "boots on the ground" in local communities who work closely with individual providers and provider organizations through the adoption process. The relationship managers became "allies" for the Beacon, as they grew to know the practices and learned when the time was right to tackle a new service such as admission-discharge-transfer (ADT) alerts. Absent that resource, it would have been difficult to do follow-ups and create a plan for when it is appropriate to adopt the transformational services with particular providers. Beacon leadership noted that the REC also does this well. Relationship managers persisted to engage with practice by getting to know the practice administrator and lead physician, assessing practices' top priorities, and determining where Meaningful Use falls in the order of priority.

Conclusion

While all of the Beacon Communities committed to developing or strengthening data exchange infrastructure in their catchment areas, each individual Community undertook these activities in a unique environment shaped by existing health care market dynamics and legal factors. The Communities also approached their development activities for health information exchange with different levels of established relationships, existing infrastructure, and technological expertise. As a result, each Community's approach to data sharing was unique to the circumstances and experiences in which the exchange solution was implemented.

Additionally, as Communities moved forward with implementing their interventions, they encountered similar challenges and enabling factors. Many Communities found that variability across practices in levels of EHR adoption, types of EHRs, and practice styles complicated the task of achieving interoperability between systems. Communities with high EHR adoption rates prior to the start of Beacon cited interoperability as a major challenge due to the wide variety of EHR systems present in the Communities. Communities also commonly reported the inability of health IT products to meet the needs of the Beacon with their "out of the box" solutions, and often had to work with vendors to develop solutions that allowed them to achieve their intended goals, delaying the implementation of some interventions. Despite varied regulatory environments, consent policies and privacy regulations for data exchange also posed challenges and delays for multiple Beacons. In most Communities, previously

established relationships, health IT infrastructure, and governance structures were crucial enablers for promoting data sharing.

As a result of implementation efforts, Communities reported several common promising practices that emerged over the course of the program. For example, several Beacons noted that the leadership of influential stakeholders helps gain buy-in from providers and the community for investing and participating in health information exchange infrastructure. Specifically, many Communities mentioned the positive effects of physician leadership to champion innovations. Many Beacons also found it crucial to build in flexibility to help practices at all levels of readiness, from smaller practices with basic health IT capabilities to large hospital systems. These common practices facilitated data sharing in many of the Beacon Communities, despite diverse baseline characteristics.

Capacity for sharing data has shaped the Communities' ability to achieve their clinical transformation objectives. Analysis of the common challenges and enablers encountered by the Communities shows that while the idiosyncratic features of local markets and legal context play an influential role in the approach a Community takes to enable data sharing, the Beacon experience produced several widely applicable lessons. Other pioneering organizations looking to undertake collaborative work in data sharing, performance measurement, and clinical transformation can learn from the experience of the Beacon Communities as they develop their own approaches and devise local solutions.