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Building and Strengthening Infrastructure for Data Exchange: Lessons from the Beacon Communities

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Background: In 2010, the Office of the National Coordinator for Health Information Technology (ONC) launched the three-year program, which provided \$250 million to 17 Beacon Communities to invest in HIT and health information exchange (HIE) infrastructure. Beacon Communities used this funding to develop and disseminate HIT-enabled quality improvement practices found effective in particular community and practice environments.

Methods: NORC conducted 7 site visits, November 2012– March 2013, selecting Communities to represent diverse program features. From August–October 2013, NORC held discussions with the remaining 10 Communities. Following each visit or discussion, NORC summarized the information gathered, including transcripts, team observations, and other documents the Community provided, to facilitate a within-Community analysis of context and stakeholders, intervention strategies, enabling factors, and challenges.

Results: Although each Community designed and implemented data-sharing strategies in a unique environment, similar challenges and enabling factors emerged across the Beacons. From a learning health system perspective, their strategies to build and strengthen data-sharing infrastructures address the following crosscutting priorities: promoting technical advances and innovations by helping providers adapt EHRs for data exchange and performance measurement with customizable IT and offering technical support to smaller, independent providers; engaging key stakeholders; and fostering transparent governance and stewardship of the infrastructure with neutral conveners. .

Conclusion: While all the Communities developed or strengthened data-exchange infrastructure, each did this in a unique environment of existing health care market and legal factors. The Communities, however, encountered similar challenges and enabling factors. Organizations undertaking collaborative data sharing, performance measurement and clinical transformation can learn from the Beacon Communities' experience.

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Keywords

Beacon Communities, data sharing, health information exchange

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Gretchen W. Torres, MPP; Karen Swietek, PhD, MPH; Petry S. Ubri; Rachel F. Singer, MPA, MPH; Kristina H. Lowell, PhD; Wilhelmine Miller, PhD, MSⁱ

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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 (HIT) and health information exchange (HIE) infrastructure.¹ The program also supported 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 served as a capstone to other initiatives implemented under the Health Information Technology for Economic and Clinical Health (HITECH) Act as it aimed to bring together the strands of other HITECH efforts to demonstrate how adoption and Meaningful Use of HIT can impact clinical processes and outcomes.^{2,3} The Communities used this funding to work on the development and dissemination of HIT-enabled quality improvement practices that have been found to be effective in particular Community and practice environments.

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Using a learning health system framework,⁴ this paper examines the Beacon Communities' approaches to and experiences with building and strengthening their HIT infrastructure, specifically with respect to successes and challenges related to the sharing of patient-specific information to improve clinical care. 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 solutions to their particular challenges.

Background

Leading policymakers have envisioned a learning health system as the path to improved quality of health care.^{5,6} A learning health system can be characterized as having the capacity to capture timely data about care provided and the results of that care, as well as enabling practitioners to use that data effectively and efficiently to deliver care to their patients.⁷ Infrastructure to exchange data electronically is the backbone of this learning health system, and it is with respect to building and strengthening the infrastructure for HIE that the Beacon Communities provide some valuable lessons.

In *Digital Infrastructure for the Learning Health System: The Foundation for Continuous Improvement in Health and Health Care*,⁸ the Institute of Medicine (IOM) Roundtable on Value and Science-driven Health Care identifies crosscutting strategic priorities for developing infrastructure to capture and use electronic health data. Three priorities are particularly relevant to the Beacon experience: promoting technical advances and innovation; engaging key stakeholders (e.g., patients, payers, and the public); and fostering governance and stewardship of the infrastructure. The IOM Roundtable describes several strategic components of each priority. In this article, the crosscutting priorities and their strategic elements frame lessons from the Beacon Communities in building and strengthening infrastructure for data exchange. In particular, the strategies employed by the Beacons provide insight about local advancement on these priorities.

Data Sharing Across the Beacon Communities

HIE is the process of electronically and securely sharing a patient's vital medical information among and across health care entities.⁹ Electronically exchanging health information supports, among other benefits, access to patient data at the point of care and facilitates the coordination of care across providers and care settings, enabling improved health care quality and delivery of care. Efforts to develop data sharing infrastructure have expanded over the years, as initiatives funded by the HITECH Act allowed Communities, regions, and states to develop HIE infrastructure or enable HIE. Under the Beacon Community Program, Communities are demonstrating how investments in HIT and HIE, and the Mean-

ingful Use of electronic health records (EHRs), advance the vision of patient-centered care, while promoting better health, better care, and lower costs.

The 17 Beacon Communities covered a wide geographic area of the United States from Bangor, Maine, to Hilo, Hawaii, and reflected a diversity of practice settings and health care challenges. Although ONC selected these Communities in part because they were already established HIT users, the Communities varied significantly in their staff and financial resources, organizational structure, and stage of adoption and implementation on of HIT.¹⁰

All of the Beacon Communities committed to developing or strengthening infrastructure for the electronic exchange of information in their catchment areas. While 7 Beacons focused on building this infrastructure largely from the ground up, 10 used program funding to strengthen or accelerate the expansion of existing systems for HIE (Table 1). Communities structured their HIE platforms in a variety of ways.

Table 1. Nature of Exchange Infrastructure Development

Infrastructure Building:

- Crescent City Beacon Community
- Delta BLUES Beacon Community
- Greater Tulsa Health Access Network (THAN) Beacon Community
- Hawaii Island Beacon Community
- San Diego Beacon Community
- Southeast Michigan Beacon Community
- Southeast Minnesota Beacon Community

Infrastructure Strengthening:

- Bangor Beacon Community
- Beacon Community of the Inland Northwest
- Central Indiana Beacon Community
- Colorado Beacon Consortium
- Greater Cincinnati Beacon Community
- Keystone Beacon Community
- Rhode Island Beacon Community
- Southern Piedmont Beacon Community
- Utah Beacon Community
- Western New York Beacon Community

Some Communities developed centralized repositories for clinical data amassed from various sources or developed connections to locally hosted and maintained repositories of data, both of which authenticated users could access by initiating queries of the requested data. Others enabled secure, point-to-point forms of exchange among authenticated providers. Differing levels of sophistication and HIT capacity are also evident through the Beacon Communities' rates of EHR adoption, which affected their ability to enable exchange.¹¹

In 2011, ONC funded NORC at the University of Chicago (NORC) to conduct an independent evaluation of the Beacon Community Program. This paper 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 HIT infrastructures, specifically their successes and challenges in sharing patient-specific information to improve clinical care.

Methods

We conducted site visits to a sample of seven Beacon Communities (Table 2) between November 2012 and March 2013. We purposely selected these seven Communities to represent a diverse set of program features, including types of HIT tools being developed and implemented; size, composition, and scope of the target-patient and provider populations; degree of sophistication of the HIE and HIT infrastructure prior to the Beacon award; scope and nature of the challenges encountered as part of building and strengthening activities; and extent of participation in other HIT programs or initiatives. During each site visit, we conducted semistructured discussions with a range of stakeholders in that Community.

In addition, from August through October 2013, we held a series of semistructured 60-minute discussions with the remaining 10 Communities. Table 2 lists the Communities that received site visits and those with which we held discussions by telephone.

Discussion topics included health care market characteristics and their impacts on data sharing within and across Communities; challenges that hindered data sharing progress; enablers that helped Communities implement HIT infrastructure; and lessons learned that could be applicable to other Communities attempting to implement similar interventions.

Across all Communities, we interviewed 56 respondents, including Beacon Community leadership committees and program staff (17); large health system and ambulatory care providers (7); care managers and care coordinators (6); Community partners (6); State (HIE) Program representatives (5); local Beacon evaluators (5); Regional Extension Center (REC) representatives (4); state public health officials (3); and Beacon Boards or Steering Committees (3).

Detailed transcripts were produced for each discussion. We developed a summary of each site visit or follow-up interview based on interview transcripts, team observations, and other program documents provided by the Community to facilitate a within-Community analysis of context and stakeholders, intervention strategies, enabling factors, and challenges to progress.

We then coded the summary developed for each Community to identify commonalities and unique factors across Communities related to health care market characteristics and their impact on data sharing within and across Communities; challenges that hindered data sharing progress; enablers that helped Communities implement HIT infrastructure; and lessons learned that could be applicable to other Communities attempting to implement similar interventions.

We present a more detailed discussion of our findings in *Data Sharing to Enable Clinical Transformation at the Community Level: IT Takes a Village*, published on the ONC website.¹² We build on that report here by examining the lessons from the Beacon Communities in terms of their advancing progress toward the creation of a learning health system.

Results: Key Lessons for Enabling Health Information Exchange (HIE)

Although each Community designed and implemented its data sharing strategies in a unique environment shaped by existing health care market dynamics, legal factors, and Communities' respective visions for how the data would be used, similar challenges and enabling factors emerged across the Beacons. This paper focuses on specific aspects of the Communities' activities to inform the work of other consortia looking to implement data sharing and clinical transformation across a region or health care marketplace.

We have articulated eight strategies that the Beacon Communities employed to build and strengthen their data sharing infrastructures and address the following crosscutting priorities of a learning health system: promoting technical advances and innovations; engaging key stakeholders; and fostering governance and stewardship of the infrastructure. Table 3 summarizes the lessons from the Beacon Communities' experiences in building and strengthening infrastructure and aligns them with the IOM Roundtable's crosscutting priorities for the digital infrastructure for a learning health care system. The discussion that follows elaborates on each lesson.

Table 2. Data Collection Strategy for Each Beacon Community

Site Visit (n=7)	Telephone Discussion (n=10)
<ul style="list-style-type: none"> • Bangor Beacon Community (Maine) • Beacon Community of Inland Northwest (Washington) • Colorado Beacon Consortium • Crescent City Beacon Community (Louisiana) • Keystone Beacon Community (Pennsylvania) • Southern Piedmont Beacon Community • Utah Beacon Community (IC3) 	<ul style="list-style-type: none"> • Central Indiana Beacon Community • Delta BLUES Beacon Community (Mississippi) • Greater Cincinnati Beacon Community (Ohio) • Hawaii Island Beacon Community • Rhode Island Beacon Community • San Diego Beacon Community (California) • SE Michigan Beacon Community • SE Minnesota Beacon Community • Greater Tulsa Health Access Network Beacon Community (Oklahoma) • Western NY Beacon Community

Table 3. Beacon Community Approaches and Lessons for Advancing the Priorities and Instrumental Strategies for the Digital Infrastructure of a Learning Health Care System

Crosscutting Priority	Strategic Element	Beacon Approaches and Lessons
Technical Progress	Workflow and Usability	<ul style="list-style-type: none"> • Build on previous collaborations and existing HIT capabilities and expertise. • Acknowledge and utilize lead time and technical support required. • Help providers adapt EHRs for data exchange and performance measurement with customizable IT systems. • Provide smaller, independent providers with technical and administrative support for data exchange.
	Security and Privacy Safeguards	<ul style="list-style-type: none"> • Work with policymakers and other stakeholders with technical expertise and resources to protect personal health information while not unnecessarily restricting data sharing.
Stakeholder Engagement	Value Proposition and User Confidence	<ul style="list-style-type: none"> • Involve consumers and influential stakeholders (e.g., payers) in decision-making to solidify support over time. • Formalize the processes and relationships necessary for data sharing to help clinical practices adopt infrastructure.
Governance	Process and Protocol Stewardship	<ul style="list-style-type: none"> • Foster trust and stakeholder confidence by using neutral conveners and transparent governance structures, especially in competitive markets.

Sources: Grossman, Powers, and McGinnis, eds. (2011) and authors' analysis.¹³

Technical Progress

Lessons from Beacon Communities in promoting technical advances and innovations for a learning health system coalesce around two strategic elements. In particular, the Beacon experience provides insight into the usability of electronic data and integration of data exchange into workflows as well as security and privacy safeguards that build trust among system stakeholders.

Usability and Integration of Electronic Data Exchange into Workflows

Previously developed IT infrastructure and expertise advanced the establishment of data sharing infrastructure within Communities. Previous collaborations and relationships were key enablers to developing data-sharing infrastructure and obtaining buy-in from stakeholders in exchanging information. Most Communities noted that governance structures, infrastructure, and relationships established through previous collaborative efforts facilitated cooperation among key stakeholders to achieve connectivity. Communities with experiences on similar initiatives or that built their Beacon initiatives on previously existing infrastructure were able to advance their initiatives and facilitate the further development of HIT.

For example, Maine's data sharing system (HealthInfoNet) was well developed at the start of Beacon funding; 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. INHS had extensive HIT expertise and resources for hosting software, creating interfaces with external systems, training programmers, conducting data mapping, and understanding architecture. They 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.

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 HIT capabilities and expertise to spread the intervention beyond Beacon practices. Mayo Clinic, the managing partner in the Southeast Minnesota Beacon Community, had an established and experienced IT department and used the same technologies for a national collaboration, 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.

Regions looking to establish a shared HIT infrastructure or implement clinical transformation initiatives using HIT should be mindful of the time and resources needed to lay the groundwork for automated performance measures, reporting, and data exchange. Several Beacons underestimated the lead time needed to prepare for clinical data exchange and practice-based performance measurement, often reporting delays in operational launch ranging from 6 months to over a year. For instance, Tulsa reported that setting up their HIE platform took 7–8 months longer than anticipated and Greater Cincinnati reported that they had been too optimistic in forecasting the timeline for completing data use agreements (DUAs), which ultimately took 10 months—much longer than expected.

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 populations and systems such as the Indian Health Service required extra effort and time, but also provided these practices—serving areas with greater needs—opportunities to benefit from clinical HIE and practice support.

The Utah, Tulsa, Rhode Island, and Greater Cincinnati Beacons all found that HIT 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 HIE system or data repository. Often, the resources of a dominant health system or REC helped with IT training and interfacing at Community-based practices for performance reporting and data exchange.

Beacons also experienced unanticipated delays in negotiating legal agreements for connectivity. In New Orleans, the Crescent City Beacon Community reported that connecting providers to the regional data exchange system, Greater New Orleans HIE (GNOHIE), took longer than expected, partly due to delays in the completion of data sharing agreements. The Southern Piedmont Beacon Community also noted that negotiating DUAs with major health care systems in its catchment area—the geographic area designated by each Beacon Community as its service area—was more time-consuming and challenging than had been anticipated; 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 in drafting DUAs.

Communities noted the importance of allocating sufficient time: to establish infrastructure; to develop necessary business use agreements or other documents needed to formalize connections; and to acquire trust and buy-in from providers, particularly among independent ambulatory practices that had not participated in data exchange previously.

The Beacons' ability to customize IT systems and their capacity to help providers adapt EHRs for data exchange and performance measurement proved to be an important element of success. Unexpected limitations in EHR capabilities often slowed the progress of Beacon Communities in developing the right technology solutions. Some Communities reported that various HIT products applied “right out of the box” were unable to meet their needs, so they often had to work with vendors to develop solutions to achieve their intended goals.

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 effort needed to extract data from EHR systems to populate a disease registry, while also overestimating the EHR data quality. This Beacon also spent more money than planned on paying con-

tractors to build the technology solutions, enhancing the registry, extracting data from their HIT system, and normalizing the data. While the Greater Cincinnati Beacon noted that the design was ultimately successful and scalable, the process took longer than expected.

Communities that hosted their own HIT infrastructure often customized their products to improve the systems' ease of use. Crescent City Beacon's choice of an open-source solution—Mirth™—for the GNOHIE system allowed the Louisiana Public Health Institute to create, manage, and control the technology infrastructure internally, enhancing the Community's workforce and organizational capacities. Crescent City Beacon also provided the resources to pursue answers and solutions beyond those that other software system vendors offered. For example, the Louisiana Public Health Institute used their HIT expertise in interfacing with vendors to develop solutions for other providers who wanted to connect to GNOHIE.

Additionally, customizable HIT infrastructure allowed Beacons to respond more quickly to any needed changes to systems that would facilitate workflow or increase 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 practices in their catchment areas within relatively short periods because of the resources the large systems could bring to bear on problems.

In order to engage smaller practices in data sharing, Beacon Communities built in flexibility to help practices at all levels of readiness, often while working with larger health systems, hospitals, and physician organizations. Because smaller practices are already burdened with the administrative tasks involved with keeping the practices running, additional administrative tasks related to data exchange impede opportunities to innovate. For example, the Hawaii Island Beacon Community found that small practices in their region did not have the time to build interfaces into local HIE systems. As a result the Hawaii Island Beacon spent more time than expected developing interfaces and grappling with technical aspects of the initial assessment, as well as in obtaining the information needed to connect and testing the service to ensure it was operating adequately.

A major challenge with engaging many physicians is their high patient care burden, which drastically limits their time for learning what they need to know about EHRs. The Beacon program provided physicians with information and support that enabled them to make more rational and better informed business decisions. Practices gained a better understanding of costs and benefits through the Beacon's efforts, such as advice about which EHRs might best meet their operational requirements and how they could reorganize their businesses to take advantage of these new functionalities.

Many of the Beacons that focused on establishing data exchange with small ambulatory practices found that these practices needed significant one-on-one support to achieve connectivity and facility with software. This is the kind of support that RECs typically provide small practices. Yet Beacons also deployed “practice coaches,” “business analysts,” or “relationship managers” to connect and train clinic staff. Beacons discovered that some practices lacked the resources or staff to maintain or even learn the capabilities of their own EHR system. 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 train them in the use of their own system.

Another influential factor regarding the type of data sharing infrastructure that a Beacon Community established was the participation of a large health plan or integrated delivery system. Several Beacons operated within an area that had a dominant health plan or integrated delivery system. More often than not, the Beacon was able to capitalize on the plan or system’s IT infrastructure and expertise to advance HIE throughout the Community. 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 the 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-third 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 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 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.

Note, however, that the level of market competition within a Community also played an important role in providers’ willingness to engage in data sharing activities. Beacon Communities operating in highly competitive environments faced some resistance from health systems in sharing data broadly with other providers in the marketplace as a matter of commercial advantage.¹⁴

Security and Privacy Safeguards

Communities worked with policymakers and other stakeholders to ensure data sharing was not unnecessarily restricted while still protecting health information. The federal, state, and local policy landscape for information exchange is complex and can have a significant effect on what information exchange looks like and the

strategies needed to drive adoption. 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 on either an opt-in or opt-out basis. To opt in, patients must actively agree, usually in writing, that their information may be shared by their provider with another provider. For opt out, it is presumed that patients agree that their health information can 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 in collecting patient consents 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, although they often devised more efficient approaches to collecting patient consents or deployed staff 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 was permitted to view their data in the clinical repository. These forms had to be manually entered into the system. Utah Beacon staff devoted a significant amount of time to supporting practices to collect patient consent. As a result of the shift in consent models, the data available through cHIE were initially very limited. The Utah Health Information Network, the organization that hosts the cHIE, has since shifted away from an opt-in policy.

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 choose their preferred approach, either opt in or opt out. The various partners established different policies. Although this “local option” approach proved challenging, San Diego Beacon leadership noted that a uniform, 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 worked with state legislative bodies to ensure that, as policies were implemented, overly restrictive regulations were not placed on HIE systems. The Greater Cincinnati Beacon operates in three states with similar privacy and security requirements—Ohio, Kentucky, and Indiana. At one point, however, the Greater Cincinnati Beacon faced the prospect of a new, restrictive consent policy in one of the states. The Beacon worked with the state to help craft language that avoided a strong requirement to have patient consent for any kind of data exchange.

Additionally, meeting administrative requirements related to the designation of Beacon activities as research proved to be more time-consuming than many Communities anticipated. Those Beacons sponsored by universities, or with universities as partners, acknowledged in particular that meeting internal university processes for the Beacon awards, including obtaining Institutional Review Board (IRB) approval for their interventions and data collection as research activities, took more time than had been scheduled for these preliminary steps in implementation.

Stakeholder Engagement

A key lesson in stakeholder engagement from Beacon Communities is the need to engage physician leaders as champions and involve other end users in decision-making and problem solving. Albeit time-consuming, this strategy demonstrates to broader provider groups the value of building and enhancing an infrastructure for data exchange and instills confidence and support for the end product. In addition, formalized processes and procedures for recruiting and onboarding participating practices engendered support, confidence, and a perceived value for participating in data exchange.

Broad constituent involvement in decision-making and the presence of influential stakeholders solidifies support for sustainable HIE organizations and activities over time. 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. The Bangor Beacon Community is notable for the degree of engagement of local physicians in constructing the Community's performance measures, selecting from or modifying endorsed measures in a spirit of inquiry and collective judgment. For the Hawaii Island Beacon Community, physicians championing the Beacon program were instrumental to moving the program forward.

Additionally, involving stakeholders in the development of HIE infrastructure helped some Beacons deepen support for the program. Community involvement in the process of developing GNOHIE in the Crescent City Beacon lengthened the time over which decisions were made. As a result of extensive consultation, however, Community members have 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.

In the Keystone Beacon, clinical workgroups across settings and practices gave stakeholders a say in the interventions. The workgroup participants shared a range of experiences so that practices learned from each other. Likewise, the Colorado Beacon established learning collaboratives that proved to be an important resource for problem solving across independent practices. Although the stakeholder engagement process is often time-consuming, without this key step, infrastructure that is developed may not serve the needs of the local marketplace and may ultimately not be utilized.

Formalizing the processes and relationships necessary for data sharing helps participating practices adopt infrastructure. Several Beacons innovated procedures and devised analytic approaches to the recruitment and onboarding of clinical practices to engage in data sharing. For example, 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 Keystone Health Information Exchange (KeyHIE).

Similarly, the Rhode Island Beacon established specific activities to take a provider through the process of adopting HIE services, such as provider portals, hospital alerts, and Direct secure email. The Rhode Island Beacon's customer relationship management system (Salesforce) supported formal adoption processes for interested participants and enrolled providers. The Beacon conducted several assessments of this system, drawing on the REC for specific standards for documents, and provided the REC with several different assessments to help the REC determine which strategies would be most appropriate to pursue with a particular practice.

The Rhode Island Beacon Community also recruited "relationship managers," who were "boots on the ground" in quite small geographic areas, and who worked closely with individual providers and provider organizations throughout the adoption process. The relationship managers became allies of the Beacon, as they grew to know the practices and learned when 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 would be appropriate to adopt the transformational services with particular providers. Relationship managers continued to engage with practices by getting to know the practice administrator and lead physician, assessing practices' top priorities, and determining where Meaningful Use fell in the list of priorities.

Governance

Lessons from Beacon Communities in governing the exchange infrastructure yield important insights in the stewardship of processes, protocols, and systems for data gathering, security, and use. Neutral third parties and firewalls were important strategies to foster trust in exchange infrastructure, particularly in competitive markets.

The perceived neutrality of and commitment to improving the region's care by the organization managing the region's data exchange fosters trust among providers and consumers. Some Beacon Communities established or benefitted from the presence of a neutral convener to establish trust and garner support from key Community stakeholders on the importance of data sharing to achieve clinical transformation.

Tulsa, for example, created a freestanding organization that would develop a common IT infrastructure to help all hospitals and practices in the Tulsa region provide better care. The MyHealth Access Network, the organization leading this effort, was charged with assessing what local stakeholders valued, so that the Beacon's goals could be aligned with those of its constituency. Tulsa involved payers to endorse the concept of establishing a neutral third party to measure performance; MyHealth offers a single location where all stakeholders can contribute data and access results.

In the Keystone Beacon Community (for which Geisinger served as the managing partner), the Community's data warehouse was established with firewalls to segregate the Keystone data from Geisinger health plan and health system data, even as the large health system provided much of the expertise for this effort. This clear separation of the Beacon infrastructure from the dominant regional health system reassured those providers who were not affiliated with Geisinger of the security of their own data. KeyHIE, Keystone's data sharing system for the region, provides patient identifiers via a master patient index to link data from separate tools. Similarly, the San Diego Beacon noted that innovation and HIE systems have to be built transparently and on neutral ground; such a collective endeavor should take care not to appropriate or shift patient market shares among plans and providers.

Note, however, that while a neutral organization can convene disparate parties, it may face sustainability challenges in building a business case independent of support from a well-resourced and technologically advanced partner, such as a large health system.

Conclusion

While all 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 HIE with different histories of established relationships, IT infrastructure in place, and technological expertise. As a result, each Community's approach to data sharing was fundamentally shaped by the circumstances and experiences in which the exchange solution was implemented. Given the diversity among the 17 Beacon Communities in these various dimensions, collectively they represent a rich set of experiences from which others can benefit as they undertake their own regional collaborations in HIE.

Despite the differences in their circumstances, 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 already in use within their Communities.

Communities also commonly reported that "straight out of the box" HIT products could not meet the needs of the envisioned system, and thus the Beacon often had to work with vendors to develop solutions that allowed them to achieve their intended goals, delaying the implementation of some interventions. Consent policies and privacy regulations for data exchange also posed challenges and delays for some Beacons, depending on their interventions and regulatory environment. In most Communities, previously established relationships, HIT infrastructure, and sound governance structures were crucial enablers for promoting data sharing.

Recent studies report that adoption of EHRs and the use of related tools have accelerated; however, applications for clinical information exchange, patient population management, and quality reporting lag behind the achievement of simpler functions.^{15,16} The Beacon experience sheds some light on these more sophisticated uses. Findings from this evaluation build on work documenting the experience of a previous generation of HIE organizations¹⁷ and confirm earlier findings of extended start-up periods due to both organizational and technical challenges, and of incremental progress in provider buy-in to HIE.¹⁸

The Beacons' experiences demonstrate how the challenges of technology, stakeholder engagement, and governance can be addressed in concerted voluntary initiatives by health care market places with collaboration among health systems, providers, public sector partners, consumers, payers, and the expertise of technology and quality improvement organizations. Other regions engaging in data sharing efforts can benefit from lessons learned from the Beacon Community Program as they develop strategies to meet their own unique and local needs.

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References

1. Health IT Adoption Programs [Internet]. Washington, DC: Office of the National Coordinator for Health Information Technology (ONC); [cited 2014 April]. <http://www.healthit.gov/policy-researchers-implementers/beacon-community-program>
2. Ibid.
3. Maxson ER, Jain SH, McKethan AN, Brammer C, Buntin MB, Cronin KC, et al. Beacon Communities aim to use health information technology to transform the delivery of care. *Health Aff (Millwood)* [Internet]. 2010 Sep [cited 2014 April]; 29(9): 1671-7.

4. Grossman C, Powers B, McGinnis JM, rapporteurs and eds. Digital Infrastructure for the Learning Health System: The Foundation for Continuous Improvement in Health and Health Care. Washington, DC: The National Academies Press; 2011.
5. Friedman CP, Wong AK, and Blumenthal D. Achieving a Nationwide Learning Health System. *Sci. Transl. Med*; 2010 Nov; 2,(57):.57cm29. http://www.networkforphl.org/_asset/3p-cp7d/AchievingNationwideLHS.pdf
6. See the mission statement of the IOM Roundtable on Value & Science-driven Health Care at: <http://iom.edu/~media/Files/Activity%20Files/Quality/VSRT/Core%20Documents/Background.pdf>
7. Grossman et al., eds., op. cit.
8. Ibid
9. Office of the National Coordinator for Health Information Technology. What is HIE [Internet]. 2014 [Cited 2014 Jul 14]. Available from: <http://www.healthit.gov/providers-professionals/health-information-exchange/what-hie>.
10. NORC at the University of Chicago. Characterizing the Beacon Communities [Internet]. Washington, DC: Office of the National Coordinator for Health Information Technology (ONC); 2013Mar [cited 2014 April]. Available from: http://www.healthit.gov/sites/default/files/norc_beaconevalcharacterizingcommunities_march_2013.pdf
11. Ibid
12. Full data sharing report available here: <http://www.healthit.gov/sites/default/files/beacondatasharingbrief062014.pdf>
13. Grossman et al., eds., op. cit.
14. See also: Adler-Milstein J, DesRoches CM, Jha AK. Health information exchange among American hospitals. *Am J Man Care*. 2011 Nov; 17 (11), 761-8.
15. DesRoches, C. M., Charles, D., Furukawa, M. F., Joshi, M. S., Kralovec, P., Mostashari, F., Worzala, C., and Jha, A. K. (2013). Adoption of Electronic Health Records Grows Rapidly, But Fewer Than Half of US Hospitals Had At Least a Basic System in 2012. *Health Affairs*, 32 (8): 1478-1485.
16. DesRoches, C. M., Audet, A., Painter, M., and Donelan, K. (2013). Meeting Meaningful Use Criteria and Managing Patient Populations. *Annals of Internal Medicine*, 158 (11): 791-799.
17. Adler-Milstein J, Bates DW, Jha AK. A survey of health information exchange organizations in the U.S.: Implications for meaningful use. *Ann Intern Med*. 2011; 154, 666-671.
18. Vest J, Gamm, LD. Health information exchange: persistent challenges and new strategies. *J Am Med Inform Assoc* 2010; 17(3): 288-294.