

# **Strategies for Creating Successful Local Health Information Infrastructure Initiatives**

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# **Strategies for Creating Successful Local Health Information Infrastructure Initiatives Executive Summary**

Health care providers and organizations have long wished to have access to the needed information about a patient for more effective diagnosis and treatment regardless of where the information was created or where it resides. While on the path to creating a National Health Information Infrastructure (NHII) to facilitate the rapid and effective transfer of patient information, several local areas have begun to share information across multi-organizational groups in their geographic area.

This report addresses three questions: what are the lessons from previous information sharing experiences, how successful are two of the current initiatives, and what are prospective success strategies for successful local health information initiatives.

The earlier health information sharing experiment was called, Community Health Information Network (CHIN). Nearly all failed. CHINs were an intellectually supported “concept”, but were not fully conceptualized at the implementation level. Most efforts were disbanded because of organizational barriers to their success, that is:

1. Buy-in because of conflicting missions and poorly conceived objectives.
2. Perceived loss of control and lack of trust in the process.
3. Lack of clear ownership over data systems and information.
4. Lack of clarity about how a CHIN would be financed.
5. Less sophisticated technology along with the perceived need for a centralized community-based data repository.

The need for these networks has not diminished. Recently several regions started efforts to share health care information with a wider community. Two of those efforts were selected for site visits—the Indianapolis Network for Patient Care and the Santa Barbara County Care Data Exchange. While the Indianapolis and Santa Barbara County health information sharing initiatives are quite different, they share a number of similar success strategies. Both have adequately addressed the failure issues of the CHINs and both are paying more attention to the people, process, and organizational issues of engaging in the sharing of health care information with a broader community.

There are stages to transforming and ensuring success of a mega goal. If key points are missed at an early stage, the probability of failure in later stages increases. A **Success Strategy Model** for creating a Local Health Information Infrastructure (LHII) is presented. The Success Strategy Model is built around a series of anticipated stages of development and growth of an LHII. A pyramid was selected to depict the phases. The base of the pyramid reflects the Philosophical Base of community attitudes and values. Next is the community Leadership Commitment for the LHII. Next is the Early LHII phase during which the details of how the system will function are clearly outlined and agreed to by the participants. The launch of and the on-going operation of the LHII are the top layers of the pyramid.

A Local Health Information Infrastructure is an important component in the US health care system. Creating an LHII requires commitment and on-going effort to ensure success, but that success is possible.

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## **Introduction**

Health care providers and organizations have long wished to have access to the needed information about a patient for more effective diagnosis and treatment regardless of where the information was created or where it resides. The hope is that complete information about the patient from multiple sources would allow the health care practitioner to make the best decision possible.

While on the path to creating a National Health Information Infrastructure (NHII) to facilitate the rapid and effective transfer of patient information, several geographic areas have begun to share information across multiple organizational groups in their regions. At the same time, some people remember the CHIN (Community Health Information Network) movement and want to be assured that today's regional patient information sharing efforts will not suffer the same end.

This report addresses three questions in the quest to understand success strategies in creating effective Local Health Information Infrastructures (LHII) as potential building blocks to a National Health Information Infrastructure. The questions include:

- What are the lessons learned in terms of success and failure in the Community Health Information Network (CHIN) experiment?
- Are the two selected Local Health Information Infrastructure initiatives using effective success strategies?
- What are prospective success strategies for creating and implementing a successful Local Health Information Infrastructure in other communities?

## The CHIN Experiment

While there have been many individual organizational attempts to share information, the effort at a regional multi-organizational level has been more elusive. One major concept that emerged in the 1990's was the Community Health Information Network movement.

- ◆ A popular system of communication created for common use by health professionals, patients and the community. This system fuses hospital information systems (HIS) with medical databases, community health information, and on-line computer services.  
<http://www.com.msu.edu/micrh/Telehealth/telemedicineglossary.htm>
- ◆ An integrated collection of computer and telecommunication capabilities that permit multiple providers, payers, employers, and related healthcare entities within a geographic area to share and communicate client, clinical, and payment information.  
<http://www.casact.org/health/glossary.htm> (Casualty Actuarial Society)
- ◆ Providers and payors within a specific area who are networked to exchange medical and administrative information among them, eliminating redundant data collection and reducing paperwork. <http://www.payorid.com/glossary.asp>
- ◆ A community-based activity that focuses on the development of a shared information database and retrieval system on patients, their medical histories and clinical and diagnostic tests. <http://www.ohanet.org/publications/glossary.htm#C>

The above are just a few Community Health Information Network definitions selected from an Internet search.

### In the Beginning

CHINs (Community Health Information Network) were a “product of their time”! The community health information movement probably started in 1990 when the John A. Hartford Foundation started its Community Health Management Information System (CHMIS) initiative.<sup>1</sup> In assessing the challenges faced by those trying to manage costs, the Foundation identified the lack of data as a common concern. For all users, it was difficult to make significant progress because the data needed to measure some dimension of performance was not readily accessible. Since assessing performance is a prerequisite for improving performance the Foundation believed that the health care system would be unable to significantly improve performance in the cost or quality areas unless data was readily available. Thus, they created the CHMIS initiative that was comprised of three key components:

- Key stakeholders in the health community.
- An electronic network for transaction flows between health industry trading partners. As transactions moved across the network, data elements were extracted and shipped to the data repository.
- A central data repository fed by the transaction system and governed by the organization.

<sup>1</sup> Rubin, RD, The Community Health Information Movement: Where It's Been, Where It's Going. 595-616. In O'Carroll PW, Yasnoff WA, Ward ME, Ripp, LH, and Martin EL, Public Health Informatics and Information Systems. Springer-Verlag, 2002.

In the 1980's and 1990's in response to the managed care movement many hospitals began to merge into what became known as integrated delivery networks. The initial integrated delivery networks appeared where the pressure of managed care was the greatest, e.g. in California, Minnesota, Missouri, Utah, etc. Along with these new systems came the need for data.

The concept of CHMIS from the Hartford Foundation looked like a panacea for the integrated delivery network mergers. In many cases it was the integrated delivery network that supported the need for a CHIN and contributed the initial finances. Large investments in CHINs to create programs for sharing patient data peaked between 1993 and 1996; with one or more CHIN efforts under way in most urban areas.

### **What Happened**

CHINs did not work. The concept of streamlining health information to efficiently and effectively support the health of the individual and the public was an intellectually supported concept; however, networks did not thrive at the practical implementation level. There are a number of reasons CHINs did not survive.

#### **Buy-In and Conflicting Missions**

Most CHINs did not create a common and shared mission in order to further develop and survive. There were **conflicting missions** because of competitive forces among the health providers within a CHIN. Many health care organizations within a community were competing for a patient's business, thus making their proprietary interests a priority. The conflicting missions led to **poorly conceived objectives** for the collaborations and wasted effort.

#### **Trust/Control**

Who should **control** the CHIN was an issue. There were questions about how to give access to those that did not contribute financially and what information they were allowed to use. In a similar, but slightly different issue was the perceived **loss of control** by some participants. This was especially true for those participants who believe that "one" organization was in control. Electronic vendors also often pushed the CHIN approach, but some suspected that their motives were to use their technology or applications as the infrastructure for the CHIN. Vendors and other hospitals that were not involved in the integrated delivery network did not want to collaborate with an approach tied to one of their competitors. This was a major reason for CHIN failure.<sup>2</sup>

#### **Ownership**

Related to a health institution's proprietary interest was the **lack of clear ownership over data systems and information**. Health institutions highly value information, as it is information that drives their business. CHINs planned for the integration of information both enterprise-wide or across institutions, therefore presenting another form of control issue.

<sup>2</sup> <http://www.nihp.org/Reports/Emerging-Opportunities-%20to-Lower-Transaction-costs.htm>

### **Financing**

There were three components to the issue of **financing** a CHIN—who should pay for what, how to develop a sustaining funding model and were all the participants in the CHIN obtaining value for their contributions. Some people within the CHIN<sup>3</sup> felt they were in a negative-value from the onset, e.g. the amount of resources to develop the system was disproportionate to the perceived value they obtained from participating in the CHIN. This occurred when the developers of a CHIN determine the value-added benefit to a community before the community identified it as a benefit itself. The CHIN developers believe that the community would see the benefits once the developed CHIN demonstrated them.

### **Data Sharing/Technology of the Day**

There were **problems with data sharing**. Most CHINS wanted a model that “wired” all data from hospitals, doctors, insurers, purchasers and others into a **large community-based data repository** where claims, enrollment, remittance, encounter, clinical outcomes and other elements would be managed for common community use. The technology and politics of sharing data into “one pot”, doomed many efforts. The **technology** of the day became a barrier. The Internet was not yet available. The technology that could potentially deliver what was wanted was both expensive and “clunky”. The central database concept that was the norm exacerbated the control and trust issue. Several CHINs were successful with creating a “distributed database” that relied on connectivity among trading partners and using common standards.

### **CHIN Summary**

By 2000 nearly all CHIN efforts failed. The concept of streamlining health information to support health care was an intellectually supported “concept”, but not fully conceptualized at the implementation level. Most CHINs were disbanded primarily because of organizational barriers to their success, that is:

1. Buy-in because of conflicting missions and poorly conceived objectives by the CHIN members
2. Perceived loss of control and lack of trust in the process.
3. Lack of clear ownership over data systems and information.
4. How the CHIN would be financed.
5. The less sophisticated technology along with the perceived need for a centralized community-based data repository.

The need for these networks has not diminished. There has never been a more opportune time to reconstruct the community information systems concept.

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<sup>3</sup> Dowling, AF. CHINs—the Current State. In: Brennan PF, Schneider SJ, and Tornquist E, eds. Information Networks for Community Health. New York: Springer, 1997.

## Local Health Information Infrastructure Initiatives

Possibly, the Local Health Information Infrastructure (LHII) initiatives are the new millennium's answer to sharing a patient's information in a geographic region. Several regions have begun to address the issues of sharing patient data within their geographic area. While there are several local health information exchanges, two were selected for further study because **their conceptual and operational models are different.** Brief information about each site is listed below. Appendix A contains a more comprehensive overview of both sites.

- ◆ The **Indianapolis Network for Patient Care** (INPC) includes all five major hospital systems<sup>4</sup> in the Indianapolis area, all four homeless care organizations in Marion County, all county and state public health departments, 85 primary care providers at 20 sites, 3000 sub-specialists, and 30 public school clinics. Together, INPC participants cover over 95% of acute inpatient and non-office based outpatient clinical care within the INPC, including more than 300,000 emergency room visits and 100,000 inpatient visits per year. Participants together contribute over 50 million laboratory results per year and all inpatient and emergency encounter summaries to the INPC. These include discharge and admission summaries, operative notes, radiology reports, pathology reports, inpatient medications, and tumor and immunization registry data. Additionally, some participants also contribute radiology reports and images, cardiology studies, outpatient medication lists, and medication prescription data from pharmacies.
- ◆ The **Santa Barbara County Care Data Exchange** (CDE) was created as a countywide regional health information exchange, to permit all authorized personnel, including patients and healthcare providers, to access regional patient clinical information from any site using a single web-based interface. Initiated in 1998 with a ten million-dollar grant from the California HealthCare Foundation, the CDE sought to determine whether a regional health information exchange was feasible, financially sustainable, and would improve the quality of patient care. Developing the exchange involved the creation of a technical, financial, organizational, and legal infrastructure. The CDE involves collaboration of public and private institutions and has operated as a public utility since December of 2001. A private corporation is currently administering the Santa Barbara County initiative. The health data exchange consists of lab reports, radiology reports and images, clinical notes, pharmacy data and eligibility and administrative data.

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<sup>4</sup> Participating hospital organizations include Clarian Health Hospitals, Community Hospitals, St. Francis Hospital, St. Vincent's Hospitals, and Wishard Memorial Hospital.

Both sites are considered Local Health Information Infrastructure initiatives by today's definition. To further investigate success strategies in both the Indiana and the California regional health information sharing efforts, on-site consultations occurred in November of 2003. Prior to the site visits an interview instrument was developed to guide the discussion and to gather the needed information. (See Appendix B) The following is a summary of the site visit findings.

### **The Indianapolis Network for Patient Care (INPC)**

The Indianapolis network grew primarily as the result of a single clinical champion who developed informatics tools and strategies and who believed in a regional system. He worked to extend the use of the system one hospital at a time. The Indianapolis network was organized as a "Switzerland" concept, e.g. as a neutral third party organization outside of health care competition.

The Indianapolis network contains tools that meet different needs to enhance adoption, e.g.

1. Indianapolis Network for Patient Care—Consists of a single networked series of databases containing standardized results from multiple care sites and a web-based electronic health record developed by the Regenstrief Institute<sup>5</sup>. It provides clinical abstracts for Emergency Departments upon patient admissions.
2. Docs4Docs and I Care Connect—A service that gathers results from testing facilities and delivers them to requestors (primarily outpatient) at a delivery cost of \$0.40 per result. This is 50% the cost that existed prior to the network.

Initially the Indianapolis network selected sharing information from hospitals to local Emergency Departments as its prime focus. This focus allowed for a contained experiment, engaged champions, provided a "good" story, and had a favorable ratio of benefit to risk in terms of the risk of sharing proprietary clinical data.

Competition between different hospital systems was predicted and there was a strategy developed to build trust among stakeholders. Trust building required time. Approximately two years were required for community members to feel comfortable with each other about this effort. Building trust took many forms, e.g. conversation (meetings, special training workshops—Harvard Business School retreat seminars), collaboration on small tasks, developing a shared vision, etc.

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<sup>5</sup> The Regenstrief Institute is an independent institution committed to conducting "research to improve health care by improving the capture, analysis, content and delivery of the information needed by patients, their health care providers and policy makers", [www.regenstrief.org](http://www.regenstrief.org).

The Indianapolis network spent a considerable amount of time on data standardization as a vital component of their system. In the Indianapolis network, all data is sent as or converted to HL7 compliant messages, then is standardized (through coding structures such as LOINC, CPT, ICD, etc.). Data standardization permits aggregation across institutions for ease of clinical review and public health reporting.

Participants in the Indianapolis site visit identified a number of success strategies that they use. They also pointed out strategies that they did not use initially, but learned through the years that they needed to use. A summary of Indiana success themes is presented in Table 1.

<b>Table 1: Success Themes of the Indianapolis INPC</b>	
<b>Theme</b>	<b>Discussion</b>
Driven by physicians toward a clinical information focus	This group determined that clinical messaging has big results for the physicians and, therefore, decided to start their effort on what was important to a large group of physicians. Physicians provided the consensus of what information is needed, standards, etc. They started with the Emergency Department as that is where the physicians initially wanted/needed the data. The LHII must be the arms and legs for the physician practices.
Strong support from the business community	This group has very strong support from the community. There is community wide buy-in from the hospitals and business leaders. The initial success strategy is that the business community came together because of what was good for the community. This is still a prevalent attitude. The community also includes the local government, national pharmacy chains, etc. This community structured itself for success over a 2 year time period.
Partners feel valuable	Partners in the INPC feel valued and trusted. They have a high desire for collaboration and connection to the INPC. This group worked one on one with each CEO, CIO, and CMO to build the relationship. Building trust took a lot of teamwork. The INPC has worked hard to ensure that everyone has a sense of control.
There was an initial champion, but now there are many champions	The Indianapolis network grew primarily as the result of a single clinical champion who developed informatics tools and strategies and who believed in a regional system. This physician/champion has an excellent national and regional reputation for cooperation.
Have a shared vision	This group developed a “big” vision and a “macro” strategy of how to achieve the vision. They felt they must keep the vision at a high level. Periodically they need to pull people back together to stay on course for the vision
Mobilized around focused concepts	This group started with a smaller concept and then outlined phases within that concept, e.g. the clinical messaging service was the concept. The phases include: Phase 1—ED data and hospitals, Phase 2—connecting to physician offices, and Phase 3—wider community involvement (e.g. value added). This is effectively a “wedge” approach to the change process, e.g. open the door with a highly desired concept and then continue to “push” open the door with more and more desired items. The wedge is metaphorically a “door-stop” to keep the door open while working on other action items.
Table 1 Continued on the next page	

**Table 1: Success Themes of the Indianapolis INPC (continued)**

Built a sustainable model for funding	This group had a preliminary ROI study that outlined potential savings for the hospitals. They also responded early to financial issues, e.g. who gets money if there is any money earned? The INPC found sustainable money by determining how to lower charges for those that are currently paying the bill, e.g. sending lab results used to cost the lab 80 cents, but with the new system it costs 40 cents. There was an initial source of funding to reduce start-up costs for participants and at the same time demonstrate the value of the INPC. This seed money was provided by the Regenstrief Institute and was small compared to the Santa Barbara seed money.
Dealt with politics in a proactive manner	This group understood the role of politics and that it would be a continuous issue. There were and are a number of issues to address, e.g. how you address getting everyone on board; a worry about what the research/academic people wanted to do; representation on the Board; etc. If there is a problem, they get the 5 or so people involved in a room and work out the solution as soon as possible.
Developed communication strategies	This group discovered that communication is a continuous challenge. They started with the ED so that they would have an easy story to tell. They developed clear messages on the meaning of the effort.
Included the health department	The public health component of the community is essential to community success. This LHII has a high value for the public health system in their area.
Developed effective change management strategies	It took the group about 2 years to get comfortable with each other and the effort. They also developed change management tools, e.g. an organizational readiness for change survey.
Paid attention to the legal issues	There is a need to develop multiple area legal agreements about a number of issues, e.g. service levels, privacy issues, consent, cross discipline viewing, etc. This group has an extensive agreement.
Developed a strong technical model	This group addressed a number of issues including: must have a way to standardize the data from the multiple sites; how to manage the repository; how to involve the CIO's in the decision making process; if there was a need for a centralized database; the standardization of data; ensuring there is one system and not duplicate systems in the community; etc.
Have a neutral managing partner	Need the managing "partner" to be considered a "Switzerland", e.g. trusted to do the best for everyone and not for self.
Have appropriate leadership groups	Need a strong committee structure for management, clinical and technical. There may only be 50 people who are involved in the effort from a strategic point of view and these people need to be continuously involved and given information. Need leadership and people skills to be successful.
Data standardization	Standardization of data feeds from the independent institutions permitted aggregation of results for public health reporting and for display to health care providers.
Monitor the system	Continuously monitor the system use by groups of people. This group monitors the use of the system on a regular basis.

## **The Santa Barbara County Care Data Exchange (CDE)**

The Santa Barbara County network has a different history from the Indianapolis network. In 1998, health care leaders in the Santa Barbara community came together to discuss the possibility of a community-wide electronic medical record pilot project. The community leaders “organized” with the assistance of the Santa Barbara Regional Health Authority, the regional MediCal health plan. The Santa Barbara Regional Health Authority served as a central, neutral organizing entity. Together, the health care leaders approached the California HealthCare Foundation for a grant in support of their vision. The community was awarded a five-year grant totaling approximately \$10million to develop a system that shared clinical data throughout the county. The Santa Barbara County group contracted with CareScience, Inc. to manage the project and ultimately develop the Care Data Exchange (CDE).

Santa Barbara County contains three interconnected regional health care markets. Each market has a dominant local hospital system and affiliated medical groups<sup>6</sup>. Because of the geographical separation, there is moderate competition between the regions enabling countywide cooperation and the creation and participation in the CDE. The CDE is governed by a leadership council (The Council) formed of senior members of anchor organizations. The Council is supported by a Clinical Advisory Committee (CAC) and a Technical Advisory Committee (TAC) represented by “data savvy doctors” and Chief Information Officers, respectively from these institutions.

The CDE emerging from its successful pilot stage involved approximately 70 pilot clinician users (physicians, nurses and nurse practitioners). In January 2004 it will be made available to approximately 200 clinicians with the ultimate goal of approximately 50% adoption by the nearly 1,000 physicians in Santa Barbara County.

As grant funding ends for CDE, alternative financial models to support and further expand the Exchange are being considered. Possible revenue models include sponsorship, transactional, connectivity or value-based models by the major health care institutions. It is anticipated that the end users, i.e. clinicians, will not be required to pay to use the system; instead data provider organization, which benefit from lower data distribution costs will fund the operation of the CDE.

Participants in the Santa Barbara site visit identified a number of strategies that they are using for success. A summary of the Santa Barbara County success themes is presented in Table 2.

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<sup>6</sup> Participating organizations included MidCoast IPA, UNILAB Corporation, Marian Medical Center (Santa Maria region); the Lompoc Valley Community Health Organization, Lompoc Hospital (Lompoc region); and the Santa Barbara Regional Health Authority, Cottage Health System, Sansum-Santa Barbara Medical Foundation Clinic, the Santa Barbara Public Health Department, Pueblo Radiology, and NDC Health (Santa Barbara region).

**Table 2: Success Themes of the Santa Barbara CDE**

Theme	Discussion
Driven by physician involvement and feedback	This group had physician involvement from its very early stages. The medical community monitors the exchange of information to ensure that their needs are being met.
Collaboration among multiple institutions	This group has spent time reaching out to and involving the Santa Barbara County health community. There is a strong collaboration from the multiple institutions within the community. There is increasing involvement from third party payors.
The value of seed money.	The development of an LHII is so complicated and time consuming that the Santa Barbara community believes there is a need for seed money to begin other LHII's.
Partners feel valuable	They have a high desire for collaboration and connection to the LHII. Based on past working relationships this group has developed a sense of trust among collaborating institutions. There is a strong sense of ownership among users.
Have a shared vision	This group understands the need for a big vision and a plan for how to get there. They have an overall goal of improving health care through enabling physicians, health care organizations and consumers to exchange clinical information across enterprises within a region. They want to create an infrastructure to promote collaboration within a medical community.
Have a strong entrepreneurial guide	The leader of the Santa Barbara Health Authority heard about the possibility of funding for a regional data sharing pilot and mobilized his network to obtain a 10 million dollar grant within a very short time period.
Mobilized around a design concept	The Care Data Exchange System has the ability to create customized views for clinicians (results reporting and communication); clinical assistants (support clinician data gathering); consumers (personal data management); as well as "push" and "pull" data capabilities.
Need for a sustainable funding model	The Santa Barbara group started with a major grant and is now in the process of developing model for a sustainable funding model.
Communication	This group has spent a lot of time on communication. They had a publicly sponsored kick-off event. There is a need for continuous communication between all institutions as their technology changes.
Included the health department	The public health component of the community is essential to community success. This LHII has a high value for the public health system in their area.
Developed effective change management strategies	This group will only engage the users when the system is ready. They outlined a diffusion strategy to move the system to others in the region. They are currently at the end of the pilot phase. They anticipate the next phase will begin in early 2004.
Paid attention to the legal issues	There is a need to develop multi area legal agreements about a number of issues, e.g. service levels, privacy issues, consent, cross discipline viewing, etc. Santa Barbara County has an extensive Care Data Exchange User Agreement.
Developed a strong technical model	This group determined their strategy of using non-standardized data would speed their rollout. However, they are actively developing a standardized data model. They are using brokered peer to peer networks rather than a central data repository.
Have a neutral managing partner	This group determined that they needed the managing "partner" to be considered a neutral third party. A private corporation manages the Santa Barbara CDE.
Have appropriate leadership groups	This group has created an effective coordinating structure consisting of management, technical and clinical leadership councils.

## **Summary**

While the Indianapolis and Santa Barbara County Local Health Information Infrastructure Initiatives are quite different, they share a number of similar success strategies. Both have adequately addressed the failure issues of the CHIN's and both are paying more attention to the people, process, and organizational issues of engaging in the sharing of health care information with a broader community. A summary of the success themes follows.

### **Similar Themes**

- Partners feel valued.
- Gained community support.
- Have a shared vision.
- Mobilized around focused concepts.
- Strong physician involvement. (The clinical information decisions are driven by physician users.)
- A strong leader. (In one group there was a strong physician champion and in the other a strong entrepreneurial guide who was not a physician.)
- The health department is included.
- A neutral managing partner.
- Appropriate leadership groups.
- Have a technical model. (The models are different from each other.)
- Effective communication.
- Effective change management strategies.
- Paid attention to the legal issues.
- Sustainable funding model (Indianapolis has a funding model and Santa Barbara knows they need to develop a funding model).
- Politics are dealt with in a proactive manner. (Indianapolis seems to pay more attention to these issues and that is probably because they are fully operational.)

### **Somewhat Different Themes**

- Data standardization
- Monitor the system (one system is completely operational and the other is just leaving the pilot phase)
- The size of the seed money

## LHII Success Strategy Model

### The Premise

There are stages to transforming and ensuring success of a mega goal. If key points are missed at an early stage, the probability of failure in later stages increases.

The following is a conceptual **LHII Success Strategy Model** that is based on successes and failures identified in the literature, the two LHII site visits, and also on personal experience. The **LHII Success Strategy Model** is built around a series of anticipated stages of development and growth of a Local Health Information Infrastructure.

A pyramid was selected to depict the phases of the **LHII Success Strategy Model**. Each phase will be explained in further detail, but briefly the base of the pyramid contains the attitudes and values that form the Philosophical Base of the LHII. This is followed immediately by the community Leadership Commitment that is necessary for success. Next is the Early LHII phase. This phase follows (or is parallel to) the Leadership Commitment phase. During this phase all the details of how the system will function are clearly outlined and agreed to by all of the participants. A small phase is the actual launch of the system, i.e. Starting LHII. At the top of the pyramid is the LHII, the on-going operation.



Figure 1: The LHII Pyramid

### Philosophical Issues

Change is not easy! Before beginning the LHII effort the overarching philosophical issues must be considered, as they will affect the total LHII, whether or not they are visible. Before a person or community decides to “champion” the LHII concept, there are philosophical issues that must be factored into the decision and the process. The following are the core philosophical concepts to consider.

1. Building an LHII is more of a political process than a technology process.
2. Collaboration is achieved through consensus built on sharing and trust.
3. The LHII must be structured so that participation does not mean the loss of power, control and/or status.
4. Being the champion for an LHII requires risk-taking behavior.
5. Participant acceptance comes in phases and requires knowledge of the participants needs.
6. Creating an LHII will take time, both in the initial work and for the length of time until it is the “new” way of working.

The time frame for this phase is difficult to predict, as each region is different. However, one question to ask, has the region been successful with past collaborations? If yes, the time for collaboration on this effort will be less. If the answer is “no” then the community needs to begin by building relationships before/as it moves forward. Based on the two site visits, Indianapolis was able to move forward as the electronic health record was championed for a number of years by a person with a positive reputation in the community. In Santa Barbara County, they relied on their past successful relationship to obtain a 10 million dollar grant in a very short time period. Given that both experiences were positive, it still took the Indianapolis people two years to be comfortable with each other. The two-year time frame is probably appropriate for Santa Barbara County, but that is hard to say as they were developing the technical system at the same time they were enhancing relationships. In his landmark book, Quality is Free<sup>7</sup>, Philip Crosby indicated that from the time a complex project is started until it is the accepted mode of operation is anywhere from 5 to 7 years. This “norm” seems to hold in the two sites studied.

Once the philosophical issues are considered and the decision is made to move forward, the next phase is getting the community leaders to accept and embrace the concept. This leadership commitment is strategically important for a number of reasons—financial, resources, etc, but to also be supportive when then process “hits a snag”. At that point you want the leaders to be supportive and not to turn their collective “backs” on the LHII.

### **Leadership Commitment —Getting the Leaders on Board**

1. There is a community consensus on the need for an LHII.
2. There is a shared vision, mission and the benefits for participation in the LHII.
3. There is a strong sense of excitement and commitment by community leaders.
4. An independent, neutral, trusted third party is selected as the coordinator.
5. There is a strong sense of ownership and participation in the process.
6. There is appropriate attention to financing the system—both initially and for the future—to ensure success.
7. There is local government support and/or involvement.
8. Appropriate champions are identified in each organization.
9. Comprehensive and effective communication strategies are in place.
10. There is a clear agreement on what participation in the LHII means

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<sup>7</sup> Crosby, P. *Quality is Free: The Art of Making Quality Certain*. New York: McGraw-Hill. 1979.

The next phase begins after the leaders have agreed (or could occur concurrently with the previous phase). This phase, tentatively called “Early LHII”, revolves around the organizational, technical, educational, financial, legal, political, and implementation processes. This phase must be completed before the first patient information is shared.

### **The Early LHII—Beyond of Leadership Commitment**

#### **Organizational**

- Establish appropriate organizational leadership groups, e.g. management, clinical and technical leadership councils.
- Establish an on-going process to monitor the total system, i.e. people, process and technology.

#### **Technical**

- Understand the potential flow of information.
- Establish standards, i.e. data, message formats, communication, etc.
- Establish the data model.
- Pilot and test the system.

#### **Implementation Process**

- Establish clear objectives.
- Create a comprehensive and integrated implementation process.
- Clearly define roles and responsibilities for everyone connected to the LHII.
- Clarify who is “in charge”.
- Establish accurate and timely two-way communications.
- Establish efficient practices and coordination between/among organizations to provide seamless continuum of information required.
- Create a process for dealing with requests or changes that are required.

#### **Educational**

- Establish the educational plan, process, and people to share information and educate.

#### **Financial**

- Gather financial support.
- Determine how to continuously monitor the financial commitments and use of resources.

#### **Legal**

- Establish the required formal agreement to outline the policies, practices, and procedures agreed to in this phase (or an earlier phase) of the process.
- Formalize the data sharing agreements.

#### **Political Process**

- Assess the ‘climate’ about the LHII to determine potential pockets of resistance.
- Identify all possible players.
- Establish trust with the players.
- Involve the needed people when needed as soon as possible.

### **Starting the LHII—“Cut over”**

- Prepare the staff for the new system.
- Inform the patients about the benefits of the new system.
- Establish communication mechanisms and share information with everyone.
- Develop appropriate education and training for those involved in the system and implement that effort as close to “go live” as possible.
- Have staff available to monitor use of the system and to respond to questions.
- Develop feedback mechanisms for all who use and/or manage the LHII.

### **LHII—On-Going**

- Establish continuous communication options.
- Establish continuous education and training options.
- Halt poor performance by anyone at any level as soon as possible.
- Assess the impact and access of the LHII.
- Complete regular user satisfaction analyses.
- Complete regular utilization analyses.
- Establish appropriate meetings to address management, clinical and technical issues.

While the above may seem complex, failure to complete any one of the phases will place the LHII effort at risk for failure at a later stage. As a further reminder—this is not an overnight process. It will take both time and concentration on the steps outlined.

### **Before Beginning**

Appendix C contains three sample checklists of the issues to be considered before a region decides to begin an LHII. The first checklist deals with the Philosophical Base level of the LHII Success Strategy Model pyramid and the second deals with the Leadership Commitment level.

If a region determines that it is ready to begin then selecting a model that will work for the region is important. The third checklist helps to direct a region toward an appropriate LHII model. This checklist allows each region to add other questions that are valuable to that region.

### **Summary**

Creating an LHII is a major commitment and cannot be accomplished unilaterally or over night. We have learned this from the successes and failures of the past. The hope behind this LHII Success Strategy Model is to convey that the Local Health Information Infrastructure is an important component in the US health care system, and that it will require commitment and on-going effort to ensure success, but that **success is possible!**

## **Appendix A**

### **Two Local Health Information Infrastructure Initiatives**

#### **The Indianapolis Network for Patient Care**

Indianapolis Metropolitan Area has a diverse set of public, private, and academic health care organizations, including 13 hospitals, a community-wide network of clinics, a countywide public health department, and homeless care centers. Together, these operations provide comprehensive health care services to the 1.6 million residents of the Indianapolis, Indiana region. Because of a long-standing focus on community-wide medical information sharing, Indianapolis has long enjoyed some degree of collaboration between separate, and often competing, health care organizations, hospitals, and clinic groups.

The Indianapolis Network for Patient Care (INPC) provides the participating organizations with standardized data in the form of merged reports of care about specific patients. The major goals of the INPC are to enhance both quality of patient care and efficiency and completeness of data collection for surveillance and research. First organized and deployed in 1995, the INPC initially sought to provide to local Emergency Departments' real-time patient health summaries containing records pooled from disparate health care systems. Initial successful demonstration of INPC feasibility led to expansion of the project to include the development of a single comprehensive electronic health record system available to all participating organizations, public health monitoring for reportable diseases, a community-wide results messaging system providing electronic or printed results, the development of a large, regional de-identified cancer database, and a registry of childhood immunizations.

Participants in the INPC include all five major hospital systems<sup>8</sup> in the Indianapolis area, all four homeless care organizations, all county and public health departments, 85 primary care providers at 20 sites, and public school clinics. Together, INPC participants cover over 95% of acute inpatient and non-office based outpatient clinical care within the INPC LHII, including more than 300,000 emergency room visits and 100,000 inpatient visits per year. Participants together contribute over 50 million laboratory results per year and all inpatient and emergency encounter summaries to the INPC. These include discharge and admission summaries, operative notes, radiology reports, pathology reports, inpatient medications, and tumor and immunization registry data. Additionally, some participants also contribute radiology reports and images, cardiology studies, outpatient medication lists, and medication prescription data from pharmacies.

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<sup>8</sup> Participating hospital organizations include Clarian Health Hospitals, Community Hospitals, St. Francis Hospital, St. Vincent's Hospitals, and Wishard Memorial Hospital.

The INPC attributes its success to four factors:

- A “neutral, third party” organizational body—The INPC evolved from over thirty years of development on electronic health record systems organized by the **Regenstrief Institute for Health Care**, an **independent** institution committed to conducting “research to improve health care by improving the capture, analysis, content and delivery of the information needed by patients, their health care providers and policy makers”<sup>9</sup>.
- A participation agreement—The **Participation Agreement** serves as a contract for all INPC participants, detailing the minimum shared data content, the required content for patient consent, and a financial penalty for withdrawing from the Network.
- A management committee—The **Management Committee** at INPC is a governing group that includes two voting members from each participating organization who review progress, discuss future development, and serve as points of contact for problems or issues. Management Committee members generally include Emergency Department physician representatives and Chief Information Officers.
- A data model—The INPC **Data Model** describes how patient and provider information flows through and is standardized by INPC systems. Participating organizations send reports and results to the INPC as HL-7 compliant messages. INPC systems then standardize all received data according to type: LOINC for laboratory results, CPT-4 for procedure names, ICD-9 for diagnoses, and National Drug Codes (NDC) and RxNorm for medications. Once standardized, data is stored in and served from institution-specific Medical Record Vaults running the Regenstrief Medical Record System software. The INPC identifies patients using a global patient registry that contains one record per assigned patient number per institution, matched by social security number, patient name, birth date, gender, and the algorithm for pattern matching described by Sideli and Friedman<sup>10</sup> for cases of ambiguity. A similar physician and provider registry maintains the index of health care providers contributing to and using data from the INPC.

To ensure **patient confidentiality** and **data security**, the INPC has several controls in place. First, all participating institutions agree to a single patient consent form that outlines how healthcare data is used in the system. Second, all data is encrypted as it is sent from institutions to the INPC and when stored in the medical record vaults. Third, all systems users require authentication by username, password and by valid IP address to access the INPC. Fourth, INPC systems log all data accessions for subsequent review.

Currently, the volume of standardized data stored in the INPC permits several real-time clinical applications. The initial usage of the INPC focused on providing summary reports for Emergency Departments. In this setting, patient registration

<sup>9</sup> [www.regenstrief.org](http://www.regenstrief.org)

<sup>10</sup> Sideli RV, Friedman C. Validating patient names in an integrated clinical information system. SCAMC Proc. 1992; 588-92

at one institution triggers a query throughout INPC systems, which then generates a single Merged Clinical Abstract and allows clinicians to access a web-based merged results retrieval system for the next 24 hours. In the Merged Results retrieval system, clinicians can access and view patient records from all participating INPC institutions. An additional service, Docs4Docs uses the INPC to capture and deliver results from disparate testing sites to the various outpatient clinics throughout the community. Docs4Docs delivers results as either printouts or as results in the Merged Results applications.

With the successes of INPC in Emergency Departments and clinics, organizers expanded its usage automatically to survey all laboratory data in real-time for reportable diseases, including infectious diseases such as Chlamydia, Gonorrhea, Meningitis, Tuberculosis, and Hepatitis C. Automatic case reporting has led to nearly 100% reporting, with reports arriving significantly faster than traditional methods. Using this system in early 2000, the Marion County Health Department was able to identify and stop a Shigella outbreak at daycare centers located in disparate geographic sites.

### **The Santa Barbara County Care Data Exchange**

Santa Barbara County, California contains many diverse communities and health care operations. The breadth of health care organizations ranges from hospital-based and large sized group practices to small office-based practices. These practices together serve varied populations, from migrant farm workers through high-income earners. Santa Barbara County approaches the large metropolis of Ventura County to the south, while remaining largely rural in the north. The various unaligned health care organizations use different proprietary commercial electronic health record systems.

The **Santa Barbara County Care Data Exchange** (CDE) was created as a countywide regional health information exchange, to permit all authorized personnel, including patients and healthcare providers, to access regional patient clinical information from any site using a web-based interface. Initiated in 1998 with a five-year \$10 million grant from the California HealthCare Foundation, the CDE sought to determine whether a regional health information exchange was feasible, financially sustainable, and would improve the quality of patient care. Developing the exchange involved the creation of a technical, financial, organizational, and legal infrastructure. The CDE involves collaboration of public and private institutions and has operated as a public utility since December 2001. It is currently being administered by a private corporation.

The CDE brings various aligned and unaligned health care operations together under a single loose and flexible governance. Rather than setting strict technical, financial, and procedural standards, the CDE governance primarily serves as an oversight body for the collaborating member organizations. The governance includes four committees:

1. The **Care Data Exchange Council**, includes senior leadership from each organization, determines policy and priorities, develops communication strategies, and addresses legal issues;
2. The **Care Data Alliances**, consists of several organizations that coordinate data sharing goals and facilitate technology deployment;
3. The **Technical Advisory Committee**, includes high level representatives from each Care Data Alliance and contributing organizations, reviews technical requirements and priorities for data sharing and integration using existing systems;
4. The **Clinical Advisory Committee**, includes physician leaders from each Care Data Alliance, develops usability requirements and strategies to enhance adoption by physicians

While all participating organizations<sup>11</sup> conform to the minimal set of requirements for data interoperability set out by the governing committees, most operational decision-making remains decentralized to the individual organizations. The minimal set of requirements, outlined in the **Care Data Exchange User Agreement**, defines the obligations, responsibilities, rights, privacy rules, and business limitations applicable for participation.

The CDE Clinical Advisory Committee, working with local physicians and health care organizations, developed a series of high-level technical requirements to enhance physician adoption of the Exchange. The Clinical Advisory Committee continues to review and update the requirements.

1. Information must include multiple clinical sources of patient data
2. Information must be patient-centric, complete, accurate, and timely
3. Information must be available at the point of care
4. Information must be accessible from multiple locations
5. Access to patient and physician information must be controlled
6. The systems must improve clinical and administrative workflow efficiency

The initial focus of the CDE was supplying data from institution to physician and institution to consumer (patient). Institutions included laboratories, pharmacies, payors, and imaging centers that were more likely to use computerized patient care systems than were individual physicians. CDE systems maintained only a patient key with sparse demographic information (such as name, social security number, address, date of birth, gender), access controls, authentication mechanisms, and linkages to external proprietary systems; all clinical and administrative patient-records are stored by the source institutions and are available through a web-based brokered peer-to-peer network. Using the published set of data integration requirements, vendors and developers of

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<sup>11</sup> Participating organizations include The Santa Barbara Regional Health Authority, Santa Barbara Department of Public Health, Sansum-Santa Barbara Medical Foundation, Clinic Cottage Health System, Catholic Health Care West Mario Medical Center, MidCoast IPA, The Lompoc Valley Community Healthcare Organization, Santa Barbara Medical Society, Pueblo Radiology, UNILAB Corporations, University of California Santa Barbara, and the Veterans Health Administration.

disparate proprietary electronic record systems built interfaces to allow data exchange through the CDE.

Working with an external consulting agency, CDE researchers investigated the financial impact on operational and clinical efficiency, although all reported outcomes take into account only operational effects. The researchers used a model that represented small, medium, and large populations, the degree of health care services' dispersion through the region, the degree by which patients receive care from one health care provider exclusively, and both implementation and support costs. The financial analysis demonstrated a probable \$1.2 million net annual benefit in Santa Barbara County, and a clear return on investment in all except very small communities and those with only a single hospital. The authors speculate that actual financial return, including indirect benefits from enhanced clinical efficiency, are likely to be even greater.

To date, the CDE has been successfully pilot tested with 70 clinicians, and another 160 have been trained, with an anticipated rollout of the system in early 2004. Diffusion beyond that group will result from a combination of marketing, peer communication, and training. The expected rate of adoption for the first round of rollout is 50% among the approximate 1,000 practicing physicians.

### LHII Summary

Each of the described LHII's started with a different strength. The following table is a comparison of the two LHII's.

LHII Attribute	INPC	CDE
Project Initiated with Extramural and Private Grant Support		✓
Project Initiated by Local Clinical Champions	✓	
Collaboration of aligned, non aligned and competing organizations	✓	✓
Support for multiple proprietary and vendor health record software	✓	✓
Governance primarily by multiple collaborating committees		✓
Governance primarily by single neutral third party organization	✓	✓
Participation Agreement detailing rights, responsibilities, penalties	✓	✓
Single Patient Consent Form across Collaborating Organizations	✓	✓
Distributed Institutional Data Storage	✓	✓
Data Storage Using Single Software	✓	
Central Storage of Patient Identification Key	✓	✓
All data coded according to Standards	✓	
Initial Goal to provide records to Emergency Departments	✓	✓
Successful Feasibility Phase	✓	✓
Results displayed in single merged user interface	✓	✓
User interface operates as free-standing electronic health record	✓	✓
Permits access for Health Care Providers	✓	✓
Permits access for Patients		✓

Table 3: A Comparison of the Indianapolis and Santa Barbara LHII's

## Appendix B

### DEPARTMENT OF HEALTH & HUMAN SERVICES UNDERSTANDING LHII SUCCESS

#### Initial Statement:

The Department of Health and Human Services is interested in learning more about success and failure of regional health information networks. These networks were originally called CHINs (Community Health Information Networks) and now are referred to as LHII's (Local Health Information Infrastructures). With the anticipation that more geographic locations would like to start an LHII, the National Health Information Infrastructure effort of the Department of Health and Human Services would like to determine how a geographic area can structure a system for the highest possible success. Your response to our questions will help with their macro goal.

Person/Group: \_\_\_\_\_

Organization/Unit: \_\_\_\_\_

Responsibility: \_\_\_\_\_

Date: \_\_\_\_\_

Person conducting the focus interview: \_\_\_\_\_

General Notes:

How would you characterize your LHII today?

#### Setting the Stage

How did your LHII start?

What were the main drivers for the LHII?

Who were the main champions?

How did you reach agreement to begin the LHII?

What were the local "political" issues that needed to be dealt with for your LHII?

#### Getting the Leaders on Board

How did you get the leaders of the organizations interested in the LHII?

What were some of the initial points of concern?

What were some of the initial points of excitement?

How were the initial financing decisions reached?

How did you identify/discover LHII champions? Were they the appropriate champions?

What are the needed characteristics for a successful champion?

How was the LHII vision and mission developed? Who participated in that development?

How did you know the early leaders had high ownership in the LHII?

Did you involve the local government in your plans? Was this successful?  
Was it worth the effort?

How did you settle on who would coordinate the LHII?

What were some of the early communication strategies that you used?

What communication mechanisms are you now using?

Did everyone in the beginning have a clear agreement on what they were getting in to?

### **The Early LHII—Beyond of Leadership Commitment**

Describe your educational plan to share information and educate people?

How is the money handled?

Who pays what costs?

How are financial commitments and use of resources monitored?

Were there clear objectives before the implementation began? How did the objectives evolve?

How were the roles and responsibilities defined for everyone connected to the LHII?

How was the day-to-day leadership determined?

Tell us more about the communication process within/between/among the LHII?

How is the delivery of information coordinated between/among organizations to provide seamless continuum of information required?

How did you create the process for dealing with requests?

What organizational leadership groups are connected to your LHII? What does each do?

- Management
- Clinical
- Technical
- Others (please name)

What is the on-going process to monitor the total system, i.e. people, process and technology?

Did you develop a process to analyze/evaluate the implementation process?

Did you assess the 'climate" about the LHII to determine potential pockets of resistance? How did you do this?

How did you identify all possible players in your LHII?

How did you establish trust with the different players?

How did you learn about the potential flow of information in you LHII?

What standards were established? Who participated? How have they evolved?

Did you establish a data model? Who participated? How has it evolved?

Do you have a formalized data sharing agreement? How do you monitor if this agreement is being met?

Did you pilot and test your LHII system?

- How long?
- Who?
- Did you make changes based on the pilot? What were they?

### **Starting the LHII—“Cut over”**

How did you prepare the staff for the new system?

How did you inform the patients?

How did you communicate and inform everyone?

What education and training did you deliver for those involved?

Do have staff available to monitor use and respond to questions?

What are your feedback mechanisms for all who use and/or manage the LHII?

### **LHII—On-Going**

Describe your on going communication about the LHII?

Describe your on going education and training efforts?

What do you do when there is either poor performance on the part of individuals or organizations participating in the LHII?

What are your strategies to assess the impact and access of the LHII?

What type of user satisfaction analyses do you do?

How has workflow changed?

What type of utilization analyses do you do?

Describe you on going meetings for

- Management
- Clinical
- Technical
- Others

What are the positive aspects of the LHII?

What are the negative aspects of the LHII?

What actions would be most helpful to strengthen the LHII today?

If you were going to make changes within your LHII, what would they include?

What are your hopes for your LHII in the future?

What are your hopes for the National Health Information Infrastructure in the future?

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**OFF THE RECORD:** Do you have any “off the record” concerns?

## Appendix C

### Are You Ready for a Local Health Information Infrastructure?

The following are two sample checklists for you to consider before beginning an LHII effort in your region. The first looks at the philosophical base for starting an LHII. The second checklist focuses on the regional leadership commitment to the endeavor.

#### The Philosophical Base for an LHII

What is the underlying philosophical understanding **in your area** regarding starting an LHII? Rate your regional possibilities for establishing a Local Health Information Infrastructure.

- Five (5) represents **already achieved** excellence or wide spread agreement about what it takes to accomplish and LHII and the willingness to participate.
- One (1) indicates the need to work on the concept as soon as possible.

Concept	Scale				
	5	4	3	2	1
We recognize that building an LHII will be more of a <b>political process</b> than a technology process and we are willing to address these difficult issues.					
We have past experience with collaboration that was achieved through <b>consensus</b> to build sharing and trust.					
The LHII in our area can be structured so that participation does not mean the <b>loss of power, control and/or status</b> .					
People know that being a champion for an LHII requires <b>risk-taking behavior</b> . We are willing to take that risk and become champions.					
Our area realizes that various participants will <b>accept the system in phases</b> . We know the participants in our region and their needs.					
We clearly recognize that creating an LHII <b>will take time</b> , both in the initial work and for the length of time until it is the new way of working.					
Score					

#### Leadership Commitment —Getting the Leaders on Board

What is the leadership commitment in your area regarding starting an LHII?

Rate your regional possibilities for establishing a Local Health Information Infrastructure.

- Five (5) represents **already achieved** excellence or wide spread agreement about what it takes to accomplish and LHII and the willingness to participate.
- One (1) indicates the need to work on the concept as soon as possible.

Concept	Scale				
	5	4	3	2	1
There is a community consensus on the need for an LHII.					
There is a shared vision, mission and the benefits for participation in the LHII.					
There is a strong sense of excitement and commitment by community leaders.					
An independent, neutral, trusted third party is (will be) selected as the coordinator.					
There is a strong sense of ownership and participation in the process.					
There is appropriate attention to financing the system to ensure success.					
There is local government support and/or involvement.					
Appropriate champions are identified in each organization.					
Comprehensive and effective communication strategies are in place.					
There is a clear agreement on what participation in the LHII means.					
Score					

## **Scoring**

If all of your check marks are in the 5 or 1 columns you already know what you must begin to do.

- All 5's—start the LHII process as soon as possible!
- All 1's—"catch your breath and get a grip!" and then develop a plan to address the philosophical and leadership concepts listed.
- However, for those of you who need numbers, here is a quick overview of the scoring.

80 = Your area is in the ready, set, go mode!

48 = Your area needs to plan, plan, and plan some more!

15 = Your area has a long way to go—starting talking to people!

## **What LHII Organizational Model Has the Highest Potential for Success in Your Region?**

The Indianapolis and Santa Barbara County LHII models are organizationally quite different. A long time community clinical informatics leader started one and the other was started in response to a perceived need and with funding from a Foundation. One is managed exclusively on a local level and the other is directed by the local level, but the technological and management component is managed by a private firm. Both add value. Which model might work best in your geographic area? Here are a few questions for you to consider in your quest to evolve your regional model. What other questions do you have to add to this checklist?

Technology developed by a local participant. Managed by a Neutral Participant in your Geographic Area	Technology developed by a non-local participant. Managed by a Neutral Outside Party
The Types of Questions You Might Ask	
Is there an information systems group that has a reputation for delivering quality services?	
Yes	No
Does that group have a reputation for cooperation at the regional level?	
Yes	No
Is the information systems group willing to engage in more involvement with the local community?	
Yes	No
Would all the potential participants in the LHII feel comfortable with the regional information systems group being responsible for the technical component of the LHII?	
Yes	No
Would all the potential participants in the LHII feel comfortable with one group in the region managing the overall effort?	
Yes	No
Add your specific regional questions here....	
Yes	No
Yes	No
Yes	No