Abstract

Over one hundred Regional Health Information Organizations (RHIOs) are under development in the United States. Many of these will fail but many will become a vital part of the Nationwide Health Information Network (NHIN). Methods: Documentation was reviewed and summarized and a core group of Vermont Information Technology Leaders (VITL, Inc.) were interviewed to ascertain lessons learned in the development of Vermont’s RHIO. Results: Issues were grouped into five major categories: early planning, organization, education and marketing, technology, and financial sustainability. Conclusion: There are a number of commonalities about all RHIOs but also a number of differences predicated on location. RHIOs must remain dynamic and learn from others in order to survive.

Introduction

The vision of a U.S. NHIN will become a reality when hospitals and health care centers implement health information technology (HIT) systems and these discrete systems are linked through RHIOs. With federal initiatives supporting many of these efforts, there is now momentum for widespread adoption of electronic health records (EHRs) and other forms of HIT designed to enhance patient safety, improve quality of care, and reduce costs. In a 2006 report commissioned by the Agency for Healthcare Research and Quality (AHRQ) on the development of state-based health information exchange (HIE) projects,¹ the authors identified 101 state-related health information exchange projects in 35 states. These projects ranged from linking EHRs to e-prescribing to fully functional RHIOs. Three states, Indiana, North Carolina, and Utah were identified as having mature RHIOs while the rest were in the planning stages.

The development of the RHIOs in those states began in major metropolitan areas. While there is potentially a greater impact of HIT on the health care environment in rural areas, there are significant challenges. The capital investment required to create a health information exchange and ongoing income to operate it are more difficult to acquire in a rural environment. The higher density of providers in metropolitan areas allows the costs to be spread further.² RHIOs started in metropolitan areas can easily expand to support rural areas since the incremental costs are small.

Other factors hindering implementation of HIT in rural areas include lack of health care professionals with HIT or medical informatics training to assist in the selection of appropriate systems and foster confidence among end users and lack of widespread access to high-speed networking infrastructure. The Stark legislation targeting elimination of perceived kickbacks and current IRS laws have hindered rural adoption of HIT.

Vermont is the most rural state in the United States as defined by percent of population living in villages of 2,500 or less. With less than ten thousand square miles and a population of fewer than six hundred thousand, the state’s health care community has a legacy of providing high quality care at a reasonable cost to all of its citizens.

It was in this challenging environment that over a decade ago VTMEDNET, the first comprehensive state-wide health information network in the country, was launched.³ Unlike the state RHIOs today, it was quite primitive, using pre-Web-based technology to deliver decision support and provide modern access to electronic health records contained in the state’s only tertiary medical center. Vermont is currently undertaking development of another state-wide network, a contemporary RHIO. Not surprisingly, despite the marked technical advances, many of the issues encountered while developing VTMEDNET have been encountered again in developing the second network.

These issues and the organizational strategies for responding to them have resulted in the formulation of a set of guiding principles or lessons learned that could assist others in the planning of...
small local or much larger area RHIOs. While all RHIOs are unique, they also share certain general problems and solutions. It is this set of problems and solutions, many of which are common to both iterations of Vermont’s health care network, that could contribute to the overall realization of the NHIN vision.

Methods

To understand the issues we reviewed documents and presentations created during the development of VTMEDNET and from VITL (Vermont Information Technology Leaders, Inc.), the core development group of the current statewide RHIO, in order to identify parallels between the two efforts.

In addition, we completed structured interviews with three of the key leaders of VITL and the Chief Information Officers (CIOs) of two of the state’s twelve hospitals who had been active in the creation of VITL. All of those interviewed were part of VITL from its inception. We digitally recorded and later transcribed the interviews which we conducted over a five day period in July 2006. In two instances, interviewees requested us not to record parts of the interview and we aggregated and summarized the information.

Results

The early history of both networks is virtually identical. In both cases, a small group of individuals came together to submit a grant proposal in response to a federal initiative, the first driven by the National Library of Medicine’s call for Next Generation Internet proposals and the current effort developed around the Agency for Healthcare Research and Quality’s (AHRQ) Health Information Technology portfolio. Neither of the proposals were funded however the groundwork had been laid and the partnerships formed to move the concepts forward.

While the second state-wide RHIO proposal was not funded, two of the hospitals did receive AHRQ HIT funding, one to address quality issues through the development of a comprehensive hospital and health care system and the second to develop a local area RHIO connecting to a tertiary care center in another state. Issues that arose from cross state exchange forced by institutional affiliations became a major problem for both network iterations.

Four of the five individuals interviewed felt that Vermont’s history of collaboration had a major impact on the development of the state-wide RHIO. There were lessons learned from both VTMEDNET and a failed attempt to establish a Community Health Information Network (CHIN). An important difference between the two earlier models was in control of the data. While the first was based on the precept of local control, the CHIN was based on a central repository to which all hospitals contributed and then had to pay the rates set by a governance board to get data out.

A major lesson learned from both VTMEDNET and VITL was the need for early and broad collaboration. While a small group could have a working knowledge of the problems and propose optimum solutions, success was dependent upon involvement across many disparate entities.

VTMEDNET was primarily supported by the state’s only tertiary care institution, but the partnerships forged included the Vermont Hospital Association, the Vermont State Medical Society, the Vermont Health Care Authority and the Vermont Department of Health. VITL was driven primarily by the CIOs of the state’s hospitals but by the time the non-profit corporation was formed in 2005, it had become a multi-stakeholder organization with providers, payers, employers, state agencies, and patient representatives.

Rather than relying solely on internal funding from the participating hospitals, the VITL group pushed for enabling legislation. The 2005 Vermont Budget Bill authorized VITL activities and provided $200,000 in seed money for two projects as well as $500,000 in matching funds.

VTMEDNET added services gradually based on identified needs of the participants. VITL also chose to move slowly by creating an incremental statewide information infrastructure. Part of the legislative initiative was to focus on a pilot project that would provide information exchange between two hospitals. The project selected was medication history, again, meeting a defined need determine by surveying Vermont health care providers.

In querying whether or not the citizens of Vermont supported the initiative, there was unanimous agreement that the hospitals, payers, and the state agencies and legislature were all enthusiastic. There was less agreement about whether or not patients and even the majority of the providers were fully informed. While each of these groups had representatives that were part of the process, there was significant concern that issues such lack of understanding about patient confidentiality protections could derail the process.

All of those interviewed felt that authorizing legislation was a good first step, however several worried that sustainability hadn’t been addressed. As one of the largest consumers of healthcare, the state government has a vested interest in insuring the
success of VITL. It could be viewed as a community utility and mandate a revenue stream based on data services. However, if the state assumed such a role, then the potential for bureaucratic control could inhibit progress.

In very rural communities, financial support for health information technology is a critical issue because of the pressure for return on investment ranging from state government to the primary care provider making the initial capital investment. Realization of quality improvement needs to be balanced against initial investments and factored into the global cost of health. It takes time to realize the benefits.

Another major obstacle to developing RHIOs in most rural areas, and certainly in Vermont, is the inability or unwillingness of health care organizations to put resources towards information technology professionals that can work to realize the RHIOs in most rural areas, and certainly in Vermont, with the final being due 1 July 2007. There is every expectation that these deadlines will be met. In addition, the Vermont Blueprint Diabetes Registry will go live on 14 August 2007.

When we queried the participants about the major facilitators for success, they identified public awareness and provider buy-in as the top two. There was a feeling that patients could drive the adoption process. Understanding the benefits in terms of patient safety and quality of care was essential to getting widespread implementation.

One of the major perceived obstacles involved the public’s perception of privacy issues. This is not surprising as Vermont has been at the forefront of the healthcare privacy during the Health Insurance Portability and Accountability Act (HIPAA) negotiations. Education about the benefits of the RHIO weighed against confidentiality issues should mitigate public concern.

While providers were generally aware of the advantages of health information exchange, most did not have a working knowledge of the concepts. VITL believes that they need to understand these concepts in order to create sustainable funding models. Other facilitators include committed volunteers, organizational partnerships, and, of course, a sustainable business model.

Identified obstacles were data ownership, governance, lack of understanding about costs and the value proposition, and fear that the state might assume more control because of its initial investment. However, allof the participants felt that the obstacles could be overcome by a good educational effort. One obstacle was not as easily solved. As those involved with such efforts recognize, there are immature national and international standards for data exchange that make the interoperability of information systems and the sharing of data difficult if not at times impossible.

When asked to share specific lessons learned from the development of VITL, one respondent replied that it was critical to review the lessons learned from the development of other RHIOs across
the country. These helped Vermont avoid several mistakes. It was also important to start with a small initiative, but not so small that the RHIO principles could not be tested.

Governance needs to be strategically designed. Every member of the initial board needs to understand that the commitment is for the common good and agree to work together. In Vermont, this resulted in the hybrid approach to data sharing using both centralized and decentralized data sources in a federated model. One respondent noted that while it is important to have attorneys on retainer, it is equally important to bring ice cream to every board meeting.

Involvement of all key stakeholders at the earliest possible time was considered paramount. While the core group included hospital CIOs representatives of state agencies, and provider and patient representatives, there was sentiment that greater early participation from the payers and business community would have moved that process forward more quickly. Again, widespread education of the public could have facilitated provider adoption and state funding.

The need for a sustainable business model was recognized, but the problem has not yet been solved. All of the interviewees fell that some sort of public-private partnership would be the only way to maintain and grow VITL. However, there is also the issue of control and how to insure that state bureaucracy does not threaten to make the vision unobtainable.

Lastly, one of the major problems identified dealt with the need for health information to cross state lines. Vermont is bordered by New Hampshire, New York and Maine, each with adjacent medical centers. All potential partners are in different stages of development of their HIT systems. Health information exchange in support of the healthcare of the citizens of Vermont must recognize that data needs to cross state lines, coordinate HIT development, and take into consideration state laws and competitive realities of this action.

Discussion

There are major parallels between the creation of VTMEDNET and VITL and these alone offer some lessons that could be used in beginning the process for establishing a RHIO. However, the lessons learned from the interviews and documents pertaining to VITL take understanding the development process and the success factors to a new level.

Both network iterations began with a dedicated core group of visionaries who identified key stakeholders and tried to garner buy-in from the groups or at least their representatives. Both sought to ascertain the one project that would meet the greatest need and have the greatest impact in terms of getting support from the participants. Both started small and grew in increments. Similarities continued, but the more mature RHIO concept presented some obstacles and offered some opportunities not present in the earlier network.

Data control is critical to today’s health care environment. The need to feel that data is protected extends beyond protecting patient confidentiality. Regardless of the level of cooperation, some degree of competition exists among health care organizations when catchment areas overlap. This is magnified when those catchment areas cross state boundaries.

The solution to data control will vary among RHIOs. Some prefer a totally distributed and linked model; some prefer a centralized data repository. However, many chose a federated model that incorporates both accessing discrete data from hospital and health care institutions while ownership remains within the organization and storing other forms of data in a central repository.

Learning from others is critical to understanding issues, however, structuring the administration of the RHIO is virtually always local and problematic. This is some ways mimics the question of data control. With RHIOs, there are a large number of key stakeholders, all wanting some level of decision-making authority. Two lessons gleaned from the earliest beginnings of VITL were the need to have detailed Bylaws laying out the membership of the board and the process of making decisions and the need to have one or more attorneys on retainer.

Very early in the planning stages, a needs assessment of the key stakeholders should be undertaken. This serves two purposes. First, it identifies the initial pilot project that could have the greatest impact in demonstrating the value of the RHIO. Secondly, it can serve as a tool to educate those who will be actively involved in the process of creating and supporting the RHIO.

Education of key stakeholders is vital to sustainability. Healthcare providers need to understand the value of the RHIO and why they should be willing to alter their workflow and pay for its use. Patients need to be educated about how the RHIO will improve patient safety and the steps being taken to insure privacy. Legislators, payers, and private industry managers need to be educated about how the network has the potential to improve the quality of care and reduce costs. Education is a marketing tool for sustainability.
While most people implementing such systems state that the technology is not the problem, VITL found that this was not entirely true. Interoperability among hospital systems, all in various stages of implementation, would prove challenging so the vendor selected needed to provide a high level scalable and sustainable system architecture that would handle HIE.

The decision to begin with a pilot project and only two hospitals has enabled the technology issues to be resolved, thus avoiding costly missteps and mitigating some of the issues encountered over wider areas with fewer providers. Another lesson learned from others but proving invaluable was the need to understand and address workflow issues to insure that the providers at the point of care have the least disruption to their work, thus achieving greater system use.

Finally, the inability of a fledgling RHIO to address financial issues and sustainability has been one of the major contributors to RHIO failures. VITL is exploring several financial models as part of its requirement to create a Vermont Health Information Technology Plan. Most agree that the state of Vermont needs to have a major financial stake in the development and maintenance of the network and treat it as a community utility, although difficult in a rural state with limited financial resources. However, there is also a role for payers and business to play in its sustainability as they will be major beneficiaries.

Conclusion

Health information exchange fostered by the creation of RHIOs holds the promise to improve the quality of care and reduce health care costs. However, regional health information organizations are challenging to establish. They are composed of different healthcare organizations with sometimes differing and even conflicting missions. While the goals of RHIOs are virtually all the same, the obstacles and opportunities in their creation can differ depending on their localities.

Two interrelated health information networks were compared and many of the success factors were identical in both. However, there were also differences, and only from studying both the successes and failures of developing and mature RHIOs and learning from these can the vision of a Nationwide Health Information Network be realized.

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References