Strong State Role in HIE: Lessons from the South Carolina Health Information Exchange

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Backed with fresh ARRA funding, SCHIEx blends business models with a strong state role and a belief that HIE is a public good.

The field of health information exchange is littered with examples of failed or defunct efforts, such as those in Santa Barbara (CA), Seattle, Cleveland, and Long Beach (CA).[1,2] These high-profile failures have raised questions about the viability of regional organizations providing the foundation for a more comprehensive, nationwide health information network. However, in recent years, statewide public-private partnerships have demonstrated early success in creating health information exchanges (HIEs).[3]

State-level efforts have proliferated, with almost every state actively pursuing some type of statewide health IT strategy focused on HIEs.[4] For example, Tennessee and Massachusetts have had initial success in facilitating the implementation of interoperability networks for the exchange of clinical and financial data.[5,6] Furthermore, the American Recovery and Reinvestment Act of 2009 has renewed efforts by funding programs to advance the meaningful use of health IT, emphasizing organizational models that facilitate nonproprietary HIE.

HIEs to date have formed on several basic organizational models, none of which are mutually exclusive. The South Carolina Health Information Exchange (SCHIEx) was developed with a blend of business models, owing its success to a multistakeholder approach that has mixed aspects of public utility with a diverse set of public and private stakeholders.

SCHIEx: Fed from a State Data Warehouse

SCHIEx provides a state-level information infrastructure for connecting local healthcare providers and other stakeholders. The network enables providers to view clinical data that include medications, diagnoses, and procedures.

Although SCHIEx began operation in 2008, the clinical data available is driven from more than 10 years of paid South Carolina Medicaid claims, as well as from information shared from participating providers' electronic health record systems.

A driving force in the development of SCHIEx has been the South Carolina Office of Research and Statistics (ORS), a service agency within the Budget and Control Board, the central administrative agency for the state. ORS is a neutral entity, with no regulatory functions within state government. Through a series of agreements, as well as a recurring proviso from the legislature to be the point of integration for state agency data, various agencies and organizations (both public and private) are able to entrust their data with ORS.

As the integration point for state agency data, ORS developed a data warehouse that included data from social services, legal and safety services, claims systems, payer databases, behavioral health, the health department, education, disease registries, and support agencies including elder, disability, and vocational services.

ORS makes a fully integrated data warehouse available to all users under a standard set of rules for access and use. In addition to providing the technical expertise for connecting the data, ORS also acts as a legal intermediary by providing legal agreement templates and assurances that the data are "owned" by the originating agency or organization and that the controls (both legal and technical) are in place for other parties to use or link with the data as approved by the originating agency.

Another driving force behind SCHIEx is the South Carolina Department of Health and Human Services, the single state agency designated to administer the South Carolina Medicaid program. As such, it has been instrumental in providing the Medicaid data in SCHIEx and using the integrated data to improve the quality of its health and human services.

HIE Models

HIEs provide the infrastructure for information exchange, including the business model, governance structure, operating principles, legal model, and technology model for the exchange of healthcare information among various organizations. HIEs and regional health information organizations (RHIOs) have struggled with development and sustainability. The causes of failures are varied, but a lack of a compelling value proposition for all stakeholders is often cited as the prevailing reason.[1]

The primary beneficiary from an HIE is often the patient, who contributes the least directly toward the HIE's development and operational costs. Other vested stakeholders, such as payers and providers, all receive varying benefits and bear varying responsibilities for the costs. A major barrier in the development of HIEs then is the identification of a model that fairly and equitably distributes the costs and benefits among the various stakeholders.
At the crux of this issue is whether HIEs should follow a private, market-driven model that requires the generation of profit and value for the participants, or if HIEs are a public good that requires public financing.[2]

RHIOs and HIEs typically rely on a mix of government and private grants in the start-up phase, with the expectation of self-sustainability in the future. The table below illustrates the variety of business models in place, distinguished primarily by their funding source and stakeholders. These four models have had varying degrees of success, perhaps in part due to their rigidity in focusing on specific stakeholders such as payers or providers.

Four Categories of Business Models

Business Model	Primary Funding Source	Primary Stakeholder Focus	Description
Not-for-profit	Grants from public and private sources	Patients	Created with a tax-exempt status, driven by a charter to help patients within their geographic base
Public utility	State government	Various	Created and maintained primarily with state and federal funds
Physician-payer collaborative	Physicians and payers	Physicians and payers	Created by physicians and payers within a geographic region for the primary benefit of those two groups
For profit	Private funding	Various	Created by private funding sources with specific return-on-investment targets

Adapted from: Deloitte Center for Health Solutions. "Health Information Exchange Business Models and the States' Role in Their Adoption." Last updated July 19, 2009. Available online at www.deloitte.com.

Notes

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2. Adler-Milstein, Julia, et al. "The State of Regional Health Information Organizations: Current Activities and Financing." *Health Affairs*, December 11, 2007. Web exclusive. Available online at www.healthaffairs.org.

Incremental Steps

SCHIEx's origin can be traced to a state-level task force in 2003 that used statistics from the ORS data warehouse to identify areas of duplication of case management. The task force realized that front-line case workers could better coordinate services if they could access the data warehouse. This resulted in a request for ORS to develop an interagency case management system.

In 2004 ORS developed a working prototype of the case management system based on the integration of the various systems in its data warehouse. Subsequently, the system was used as the technical foundation for AccessNet, a single point of access to the healthcare system for the uninsured and underinsured in a three-county area of South Carolina.

In 2006 ORS partnered with a vendor in the development of a production-level master patient index (MPI) and record locator service (RLS). The company donated the software supporting the MPI and RLS, which is at the heart of integrating the different physical records found in the various systems into one logical view of the patient. Development of the MPI/RLS was completed in 2007 and used in July 2007 to provide connectivity for the Lakelands Rural Health Network located in a six-county area in northwestern South Carolina.

In July 2008 ORS launched SCHIEx, an electronic health network for the state's 700,000 Medicaid beneficiaries. Based on the MPI and RLS, the SCHIEx network allows healthcare providers to view more than 10 years of Medicaid claims data stored in the ORS data warehouse. The claims data provide health information including diagnoses, prescriptions, and procedures that enable a provider to either directly assess or infer a patient's health record.

SCHIEx is currently in limited production use, with a configuration outlined in the figure "SCHIEx Core Services." Community health centers, free medical clinics, and rural health clinics began connecting to SCHIEx in 2008 as both data consumers and data providers. This project, "Connecting Communities of Care," was funded by the Blue Cross Blue Shield of South Carolina Foundation and provides for data exchange for a minimum of 30 sites per year over a three-year period.

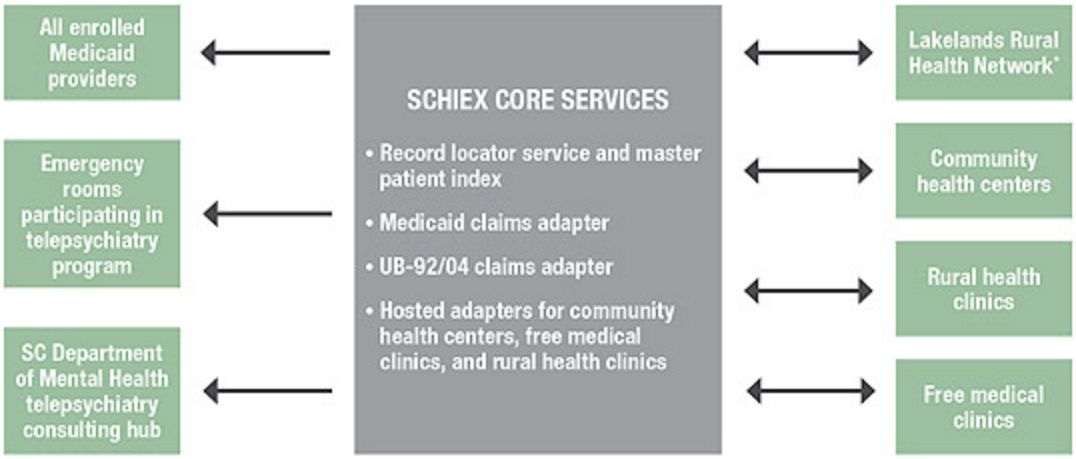
SCHIEx is also the records exchange solution for a South Carolina Department of Mental Health-sponsored telepsychiatry initiative that provides around-the-clock behavioral health consulting services to hospital emergency departments on a statewide basis. Beginning with a "push" of existing information to both ends of the consulting process, future plans include the real-time integration of the South Carolina Department of Mental Health electronic medical record.

In March 2010, the South Carolina Department of Health and Human Services received a $9.5 million dollar grant from the Department of Health and Human Services to scale the pilot initiatives that are a part of SCHIEx into a fully operational and sustainable statewide HIE.

SCHIEx Core Services

The South Carolina Office of Research and Statistics hosts the HIE's core services, which include a record locator service, master patient index, and adapters that provide interfaces for exchanging data between sources

such as Medicaid and community health centers. Adapters represent a scalable solution for adding new data sources and users to the HIE.



*Includes one regional hospital, three rural critical access hospitals, and more than 20 primary care providers covering a six-county area.

Lessons Learned

SCHIEx's success to date is the result of six key drivers. Each provides insight into how a neutral government agency such as South Carolina's ORS can facilitate the start-up of an HIE.

Facilitate Interoperability with a Federated Architecture

Following guidelines of the Markle Foundation, SCHIEx is built upon a federated, peer-to-peer exchange architecture that provides health information for more than one million residents. Disparate databases are interconnected in a way that minimizes a central authority but still supports partial sharing and coordination among database systems. In contrast to a central data repository, a federated database is a fully integrated, logical composite of various constituent databases.

Data remain physically located in various source systems, not in a central repository. A client request for data goes through two stages. In the first stage, a request is made to the RLS, which returns locations of relevant records. In the second stage, the client contacts the peer organizations identified for retrieval of the actual records.

Using an RLS, data can physically reside at any data center, enabling flexibility in the development of the HIE's technical infrastructure. In addition, this approach can alleviate the security and privacy concerns raised by a central repository that holds a comprehensive set of medical data.

Privacy and security concerns are also addressed further by using a "blindfolded" record linking approach. In this approach, the likeness or similarity of patient demographics is used for record matching, not the actual demographics.

To ensure the accuracy of this blindfolded, two-stage approach, ORS manually reviews a statistical sample weekly. In addition, Lakeland RHIO, a SCHIEx end user, conducted an audit of 100,000 records generated in this approach and found no problems. In the three years of production use, no false positive errors have been reported.

Address Data Ownership and Privacy from the Start

Protecting the privacy of individuals has always been a key consideration of SCHIEx. Each agency maintains control over its own data within the warehouse and oversees the principles and protocols for its release. Further, agencies and organizations can entrust their data to ORS because it is a service entity of the state government and part of the State Budget and Control Board.

Prior to deployment, the state engaged in numerous discussions with other states and the federal government regarding the appropriate measures to take to ensure that the health information shared would not violate consumer privacy rights.

When SCHIEx first launched in 2008, it was seeded with the Medicaid claims data. An analysis of various state and federal privacy laws was conducted to strike a balance between information availability in SCHIEx and the privacy rights of Medicaid beneficiaries. With SCHIEx and the Medicaid data, South Carolina adopted an opt-out program, where all Medicaid beneficiaries were informed that their claims data would be included in SCHIEx and given the opportunity to opt out of the program.

As South Carolina moves forward in developing a statewide HIE, it will be necessary to continue revisiting the issues of privacy and security in the context of an ever-changing legal and policy environment. At ORS, this continuous focus on privacy is facilitated by a full-time, certified privacy officer who works with the privacy officers and legal counsel of SCHIEx participants and partners.

Demonstrate Value Early

By leveraging the data already available in its warehouse, ORS was able to seed the data available from SCHIEx with longitudinal records of more than four million state residents. This includes all Medicaid claims data (including pharmacy and physician office visits), as well as UB-92 inpatient, ambulatory surgery, and emergency department claims. As a result, SCHIEx provides a nearly comprehensive record of all providers who have served a given patient or clinic since 1996.

Additionally, the Medicaid claims data are supplemented with “clinical data adapters” that can connect national lab vendors, prescription history sources, the state immunization registry, and local and regional EHR-enabled systems. The end result is an extensive data set of patient information from the very beginning of SCHIEx.

Target Pain Points for Key Stakeholders

From the beginning, ORS focused on identifying the data that agencies wanted and encouraging those private and public data owners to participate. The motivation was to fix a pain point for practitioners.

Given this approach, the selected starting point was hospital billing data, which generated a high level of interest and jump-started participation. Next to be added were Medicaid, mental health, and emergency room data. Personal relationships were important in building trust that ORS would be a good steward of the data.

The HIE team acknowledges that the success of its approach was at least partially driven by these personal relationships. Thus a critical component of SCHIEx’s success was ORS’s position as a neutral, trusted agency benefitting from long-standing relationships with key stakeholder groups. Private-sector startups that attempt to build health information exchanges can lack this advantage.

Partner with Public and Private Organizations

Although ORS provided much of the leadership in SCHIEx’s development, multiple public and private organizations provided key support to the effort.

From the private sector, CareEvolution donated much of the software technology for the exchange. From the nonprofit area, initiatives focused on the uninsured were sponsored by the Blue Cross Blue Shield of South Carolina Foundation and the Duke Endowment. From state government, the South Carolina Medicaid program is able to provide access to the Medicaid claims data.

All of these partners played an important role in forming the exchange. With the partnership approach, nearly $6 million has already been invested by both public and private sources in the development of the HIE capacity in South Carolina.

Take Small Steps

SCHIEx followed an incremental approach in its development that emphasized frequent adaptation to the changing environment. The development was not the result of a single, massive systems development project, as was the case of the Santa Barbara Exchange, which took more than five years to progress from conception to prototype.[7] In contrast, SCHIEx evolved as integration opportunities presented themselves.

At each opportunity, ORS technical staff increased its expertise in data warehousing and data integration. As outside technology and its own expertise matured, ORS recognized the value of implementing a commercial, production-ready master patient index. Originally ORS developed its own master patient index software, but as the size and scope of the project increased, ORS determined the advantage of leveraging a commercial software provider. ORS's incremental approach enabled the HIE to develop by building on prior knowledge and experience.

Next Steps: Long-Term Governance, Sustainability

Beyond initial implementation, HIEs face a separate and significant challenge: establishing long-term sustainability. Although ORS has nurtured the initial development of the HIE, SCHIEx required a more permanent governance structure. The American Recovery and Reinvestment Act of 2009 provided an opportunity to focus on sustainability.

When the legislation was signed in 2009, three key stakeholders joined to develop a cohesive plan to move forward on a permanent, statewide HIE: ORS, the state Medicaid agency, and Health Sciences South Carolina, a public-private partnership consisting of both healthcare systems (e.g., Palmetto Health) and research universities (e.g., University of South Carolina, Medical University of South Carolina, Clemson University). In March 2010 South Carolina received a $9.5 million award to transform SCHIEx into a sustainable HIE for South Carolina.

The governance of the exchange remains a critical issue for SCHIEx. Through an executive order by the governor of South Carolina, an interim governance committee was established to recommend strategies and policies to successfully implement and sustain a statewide HIE. The interim 11-member committee consists of representatives from public and private stakeholders, including a consumer representative. Its objective is to create a permanent governing body for the statewide HIE.

Similar to the interim committee, a multistakeholder approach is envisioned for the permanent governance structure. The permanent governance committee will have responsibilities such as establishing privacy and security policies, planning operations, marketing to the provider community and other end users, and establishing the agreements and contracts for participating and financing a statewide HIE. Whereas the interim governance committee was created by an executive order by the governor, the permanent governance structure requires legislation by the South Carolina General Assembly.

Currently, SCHIEx charges no transaction or subscription costs to hospitals or providers. It is subsidized primarily by the participating government agencies (more than 80 percent of the funding), with the remaining funds coming from grants and other public sources. Longer-term, it is envisioned that SCHIEx will be sustained in part by user fees. The permanent governance committee will be developing pricing strategies to cover both initial connection to the HIE by new subscribers, as well as by recurring monthly or annual fees.

SCHIEx has evolved under a model that positions HIE as a public good. Just as the government provides much of the physical infrastructure support for building roads and highways, there is a case as demonstrated by SCHIEx for government agencies to assume responsibility and leadership for building the technical infrastructure that bridges disparate systems in the formation of health information exchange.

Notes

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