Abstract

The state of Massachusetts has significant early experience in planning for and implementing interoperability networks for exchange of clinical and financial data. Members of our evolving data-sharing organizations gained valuable experience that is of potential benefit to others regarding the governance, policies, and technologies underpinning regional health information organizations. We describe the history, roles, and evolution of organizations and their plans for and success with pilot projects.

In 2004, President George W. Bush established the Office of the National Coordinator for Health Information Technology (ONCHIT) for the purpose of encouraging adoption of electronic health records, creating a National Health Information Network, coordinating federal health information technology (IT) expenditures, and fostering creation of local facilitators of clinical data exchange known as regional health information organizations (RHIOs).

Since most RHIO activity is relatively recent, local, state, and regional leaders looking to form RHIOs have few successful examples from which to draw. Massachusetts was an early adopter of community-wide health care IT projects and therefore has more experience with RHIO-like activities than many other states. The history of data-sharing organizations and efforts in Massachusetts provides a model and related experience that the authors believe may be useful to other evolving RHIOs nationwide.

To an outsider, the Massachusetts community health IT landscape presents an array of cross-institutional collaborations. The four major community-wide organizations (the Massachusetts Health Data Consortium [MHDC], the New England Healthcare Electronic Data Interchange Network [NEHEN], MA-SHARE, and the Massachusetts eHealth Collaborative [MAeHC]) have seemingly similar missions and overlapping members and leadership. Yet, closer examination shows a strong “division of labor” among these organizations, with each playing a key role in accomplishing the overall RHIO objective of facilitating regional data exchange.

While there are potentially many ways to divide up RHIO activities, Massachusetts devised four separate roles: the convener, the transactor, the grid, and the last mile. As described below, these four organizations perform these distinct but complementary roles in a way that fully addresses the overall mission of increasing diffusion of clinical IT to improve the quality, safety, and cost-effectiveness of health care. Taken together, this virtual RHIO offers one operational model for achieving the objectives envisioned for RHIOs.

In this article, the authors describe our organizations, their roles, and their efforts to date in hopes that others may gain from this experience. The participating organizations’ roles and contributions will continue to evolve as their ideas and products come to fruition.

The Convenor: Massachusetts Health Data Consortium

In 1978, after 2-1/2 years of negotiations and six years of planning by the Office of State Health Planning in response to federal initiatives, the MHDC was founded as a nonprofit coalition of the public and private health care organizations of the Commonwealth to develop a system for collecting, organizing, and disseminating data on all hospital care in the state. For the first time, this required that competing hospitals in Massachusetts share their deidentified discharge data with each other.

The development of the MA-SHARE Record Locator Service and Clinical Data Exchange was funded in Massachusetts by the Connecting for Health project of the Markle Foundation, the eHealth Initiative, and by the Robert Wood Johnson Foundation.

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In 1995, Massachusetts data-sharing activities led to the creation of the MHDC Affiliated Health Networks of New England and Chief Information Officer (CIO) Forum working groups. The CIOs from payers, providers, and employer groups agreed to meet on a monthly basis to discuss the use of IT to streamline health care commerce, reduce costs, and enhance care delivery processes. Early work included common privacy/security guidelines, common data sets for describing clinical encounters, and early discussions of how organizations could collectively address HIPAA compliance issues as a region rather than a series of disjointed efforts.

In 1997, at an MHDC-sponsored security conference, several CIOs of the payers and providers of Massachusetts gathered at dinner to discuss the creation of a network for the exchange of claims, referrals, and benefits/eligibility transactions in Massachusetts. The group named the effort the New England Healthcare Electronic Data Interchange Network or NEHEN.

The Transactor: NEHEN

Three provider organizations (Partners Healthcare, CareGroup, and Lifespan) and two payer organizations (Tufts Health Plan and Harvard Pilgrim Health Care) worked together to formally create NEHEN LLC as an independent organization. Computer Sciences Corporation (CSC) was hired to manage a regionwide administrative data exchange effort, and by October 1998, eligibility data began flowing among these early NEHEN members. Boston Medical Center joined in December 1999. University of Massachusetts Memorial and Boston Children’s Hospital joined in February 2000. As of 2005, more than 10 million administrative health care transactions in Massachusetts flow over the collaborative NEHEN network.

This early work on transaction exchange built trust among the CIOs and established a business model that all could understand—cost avoidance. Before NEHEN, transactions such as claims cost $5.00 per transaction in labor to submit via paper and e-mail. After NEHEN, these transactions could be exchanged electronically for 25 cents per transaction. Suddenly, the payers and providers in the state could potentially save millions of dollars on transaction costs and could redirect these health care allocations toward patient care instead of overhead.

The Grid: MA-SHARE

Successes with NEHEN led to the next MHDC “business incubator” project, MA-SHARE. The purpose of MA-SHARE is to foster improvements in community clinical connectivity, enabling appropriate sharing of interorganizational health care data among the various participants in the health care system, including patients, clinicians, hospitals, government, and payers. Its operating goal is to serve as the clinical “grid,” providing community utility services that support secure clinical data exchange just as NEHEN provides administrative data exchange. A community grid is only valuable if it meets the demands of its customers. After conducting focus groups and many conversations with stakeholders, MA-SHARE determined that three community utilities would best serve the needs of the state.

Identifying the Patient

First, there must be a common means to link patient data together across different sites of care. Early in MA-SHARE investigations, participants realized that a national or regional patient identifier would be too time-consuming to create and would be opposed by privacy groups who argue that a universal identifier poses too great a threat for privacy breaches. In addition, use of such an identifier would necessitate a massive retrofit of existing IT systems, which already have institution-specific medical record numbers. Working groups of the MHDC and the Markle Foundation’s Connecting for Health Initiative spent a year on the problem of patient data linkage and designed an approach that can be layered on top of our existing health care IT infrastructure: the record locator service (RLS). Other groups active in this area have adopted different data interchange strategies with varying degrees of centralization, but all have implemented the notion of a regional master patient index or RLS. The MA-SHARE RLS will be a community-wide master patient index that contains no clinical data but does contain pointers to the sites at which a patient has received care.

With patient consent, a record documenting the occurrence of each patient encounter will be forwarded to the MA-SHARE record locator service as part of each institution’s registration process. Since no clinical data are forwarded to the RLS, the potential for privacy violations will be minimized. A sample entry for the RLS might appear as follows:

<table>
<thead>
<tr>
<th>Name: John Q. Patient</th>
<th>Date of Birth: 01/01/1960</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institution: Beth Israel Deaconess</td>
<td>Identifier: 123456789</td>
</tr>
<tr>
<td>Institution: Dr. Flier’s Office</td>
<td>Identifier: 567890</td>
</tr>
<tr>
<td>Institution: Personal Health</td>
<td>Identifier: 55555555</td>
</tr>
<tr>
<td>Record at webMD</td>
<td></td>
</tr>
</tbody>
</table>

The RLS will function as a cross index and provide a list of all locations that may contain data. Participants realize that simply recording the occurrence of a patient encounter at some locations may be disclosing of a clinical condition, as indicated in the following example:

<table>
<thead>
<tr>
<th>Institution: Regional Drug Treatment Center</th>
<th>Identifier: 11111111</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institution: County HIV Clinic</td>
<td>Identifier: 22222222</td>
</tr>
</tbody>
</table>

By requiring consent, the RLS will ensure that the patient remains in control of the institutional entries that are maintained in their individual RLS. The goal of the RLS prototype is to show that a group of institutions, with no other formal affiliation, can securely use the Internet to connect to one another and find and exchange records as needed for patient care; that they can do so without requiring a unifying patient identifier or a central store of clinical data; that the system can allow participation even by relatively technically unsophisticated institutions and clinical practices; and, that the accuracy, responsiveness, security, and scalability of this prototype system will merit broader deployment.

In Massachusetts, the prototype roll out began in August 2005.

Exchanging Clinical Data

Once the RLS is available, it can serve as the foundation for the second major MA-SHARE project, the Clinical Data Exchange (CDX). One major driver for such exchange is the desire to reduce medication error in the state. The Institute of Medicine’s Crossing the Quality Chasm and To Err Is Human reports emphasized that medication error is one of the major quality issues of our time. Over 98,000 preventable...
The initial exchange of clinical data in Massachusetts will include medications and laboratory results. By contrast, the data exchanges in the Indianapolis RHIO now include a clinical summary of medications, allergies, visit history, and results.\(^9\) Massachusetts was chosen for the data exchange project by the Connecting for Health Initiative because of its early experience with a 2004 MA-SHARE pilot project for medication history exchange called MedsInfo-ED. The MedsInfo project, funded in part by the eHealth Initiative, linked together medication history data from pharmacy benefit management, health plan, and MassHealth (Medicaid) databases to provide emergency physicians with a comprehensive list of patient medications that were reimbursed by insurers. Many lessons learned in the MedsInfo-ED project about regulatory issues, data standards issues, and privacy/security issues will be incorporated into the next generation CDX infrastructure. For example, a regulatory obstacle encountered during MedsInfo-ED was that state privacy laws prevented the sharing of mental health and human immunodeficiency virus medication prescription data.

### Table 1: Early Regional Health Information Organizations

<table>
<thead>
<tr>
<th>Organization</th>
<th>Established</th>
<th>Members</th>
<th>Governance</th>
<th>Services</th>
<th>Architecture</th>
</tr>
</thead>
<tbody>
<tr>
<td>CA: Santa Barbara County Care Data Exchange</td>
<td>1998</td>
<td>Hospitals, public health department, staff model physicians, independent physicians, hospital and send out labs, state Medicaid plan</td>
<td>10 Board members, 3 officers, each with 1 vote</td>
<td>Record locator service, clinical data exchange</td>
<td>A central master patient index with distributed peer to peer exchange of clinical data and federated authentication</td>
</tr>
<tr>
<td>IN: Indiana Network for Patient Care (INPC)/Indiana Health Information Exchange (IHIE)</td>
<td>1994/2004</td>
<td>Hospitals, physicians, clinics, public health, labs, radiology centers, local government, medical societies, economic development</td>
<td>INPC has a management committee, IHIE a community board</td>
<td>INPC offers clinical summaries, longitudinal patient record, clinical reminders, electronic laboratory reporting, syndromic/statistical surveillance, clinical messaging, etc.; IHIE offers clinical messaging</td>
<td>Centrally managed federated databases with central global patient index, provider index, and federated authentication</td>
</tr>
<tr>
<td>MA: Mass Health Data Consortium/MA-SHARE</td>
<td>1978</td>
<td>Payers, providers, employers, patient advocacy groups, state government, and IT vendor partners</td>
<td>Board of managers with 1 member/1 vote authority on all decisions</td>
<td>HIPAA transaction exchange, record locator service, clinical data exchange, e-prescribing utility</td>
<td>A central master patient index with distributed peer to peer exchange of clinical data and federated authentication</td>
</tr>
<tr>
<td>NY: Taconic Health Information Network and Community (THINC)</td>
<td>2001</td>
<td>Hospitals, physicians, labs, clinics, government agencies, medical societies, payers</td>
<td>Collaborative steering committee advises MedAllies (the technical service bureau)</td>
<td>Community data exchange, clinical messaging, referral management, physician/patient communication, e-Prescribing, electronic health records, practice management system</td>
<td>Central master patient index with a clinical data repository; peer-to-peer exchange contemplated</td>
</tr>
<tr>
<td>TN: MidSouth eHealth Alliance</td>
<td>2004</td>
<td>Provider focused with some plan and clinician involvement; employers, patient advocates, vendors to be incorporated initially through advisory board</td>
<td>Board of managers with 1 member/1 vote authority on all decisions</td>
<td>Record locator service, clinical data exchange</td>
<td>Central master patient index; initially a physically “central” clinical data and authentication but designed in a manner that will allow a decentralized model to evolve if appropriate</td>
</tr>
</tbody>
</table>
ePrescribing
In addition to needing complete information about existing medications and allergies, providers must complete an often complex workflow to order new medications. In recent years, there has been a major push to automate this workflow. However, the current marketplace for ePrescribing software is heterogeneous, and there is no single solution available that electronically manages all aspects of this prescription transaction. Some companies provide systems that route prescriptions to pharmacies, others provide connectivity to payers, and others connect to pharmacy benefits managers/ mail order fulfillment firms.

We are implementing MA-SHARE’s third community utility service, an ePrescribing gateway, in order to electronically connect existing prescribing components through a common infrastructure that links prescribers to required patient information (e.g., eligibility, benefits, formulary), regardless of which payer is involved, and also connects them to retail pharmacies, mail order programs, and order fulfillment locations to deliver new prescriptions, renewals, and changes.

Like NEHEN, this gateway is a community utility that enables electronic interaction among all the constituents in a multistakeholder workflow. Imagine that a provider writes a prescription for John Q. Patient for the medication Nexium. The e-Prescribing gateway would do the following:

1. Query regional payers for pharmacy coverage eligibility for the patient. The result—John Q. Patient is confirmed as an insured patient who is eligible for outpatient pharmacy reimbursement with a $5.00 copay per medication.
2. After identifying the payer and confirming eligibility, the gateway checks the medication against a payer formulary. For example, Nexium (esomeprazole) is not included in the formulary and Prilosec (omeprazole) is the recommended equivalent medication.
3. After performing the therapeutic substitution (Prilosec for Nexium) with provider and patient consent, the gateway forwards the prescription to the retail pharmacy or mail order pharmacy selected by the patient, which fills the prescription and submits a claim to insurer’s pharmacy benefits management firm for payment.

Although many commercial firms may be involved in providing the workflow described above, the ePrescribing gateway will provide a single community-wide infrastructure that eliminates much of the complexity of creating multiple legal agreements and interfaces with each institution and provider office. The payers and providers of Massachusetts have agreed to fund the creation of the ePrescribing gateway and initial implementation is planned for the end of 2005.

By providing the RLS, the CDX, and the ePrescribing gateway, MA-SHARE will become the clinical information grid for the state. MA-SHARE has incubated several projects in the past two years, including the development of a national standard for secure e-mail, credentialing simplification, and various research initiatives. For example, the secure email project resulted in the creation of an RFC for S/MIME gateways that enable organization-to-organization rather than person-to-person secure e-mail. This technology is being piloted by one payer and one provider in Massachusetts as an early evaluation of its potential statewide application.

Although further development of these incubated projects may be incorporated into future MA-SHARE offerings, at present, MA-SHARE is focused primarily on the three projects described above.

The Last Mile: MAeHC

Having a clinical information grid is only useful if providers can connect to the statewide infrastructure. Realizing that only 15% of the providers in Massachusetts use electronic health records, project members realized than an important step in creating community connectivity is to ensure wiring to the “last mile” of the provider office. In 2004, the Massachusetts Chapter of the American College of Physicians adopted as their top priority the promotion of universal adoption of electronic medical records in physician offices in Massachusetts. At the same time, Blue Cross/Blue Shield of Massachusetts was contemplating investing $50 million to spearhead greater adoption of electronic medical records in the state. Leaders of these two efforts led the launching of a collaboration of 34 organizations to oversee a pilot project to implement electronic health records in three communities in Massachusetts in order to evaluate the impact of health care IT on quality and cost in the provider office. The MAeHC was formed to execute this project. In March 2005, three communities were chosen based on their patient mix, geographic location, and IT sophistication. Over the next 18 months, we will implement electronic health records and connectivity infrastructure throughout these three communities and evaluate the impact on quality of care and cost. The MAeHC’s mission is to use the lessons gained from these pilot projects to spearhead the universal adoption of electronic health records across the state, engaging payers, providers, patients, QIOs, and employers in the process.

This last mile role is key to the success of our statewide network. Grids of connectivity and electronic transactions are only useful if clinicians have the software and hardware to store clinical records electronically. In addition to MAeHC, other organizations will also work with clinicians to complete the last mile. These organizations include providers such as CareGroup, Boston Medical Center, Partners HealthCare, and MassPro, the state quality improvement organization.

Thus, as of 2005, Massachusetts has four organizations to foster health care connectivity: MHDC, the convener, educational organization, and business incubator; NEHEN, the grid for community exchange of administrative data; MA-SHARE, the grid for community exchange of clinical data; and MAeHC, electronic health records and the “last mile” connection of services to provider offices.

We recognize that creating community-wide connectivity for health care is not principally an IT project. The infrastructure built by the organizations described above must be solidified and institutionalized by standards and policies that facilitate the exchange of data. Major issues such as privacy, security, organizational trust, patient consent, and standards adoption are prerequisites to IT implementation, and lack of agreement on such issues has stifled the creation of many prospective RHIOs across the country. All four of our organizations play important roles in standards and policy formation and adherence.

Standards and Policies

The MHDC has served as the primary educational and convening organization to address health care IT issues in the
state. In addition to convening the CIO forum, it also convenes two important committees: the Privacy and Security Officers Forum and the Technical Advisory Board.

**Privacy and Security Officers Forum**
The MHDC Privacy and Security Officers Forum is a multi-disciplinary group composed of payers, providers, employers, government regulatory agencies, patients, and legal experts. Its purpose is to ensure that all our community efforts comply with HIPAA, statewide regulations that preempt or expand on HIPAA, and community best practices. Issues such as patient consent, disclosure, data sharing for purposes other than treatment/payment/operations, and technical mechanisms to protect patient privacy are discussed and agreed on as a community.

**Technical Advisory Board**
All our data exchange efforts require that commonly adopted industry standards be used to facilitate integration of existing electronic systems. However, this requires agreement on common use of standards, common mechanisms for controlling access to data, and common means of securely transporting data. The Technical Advisory Board discusses the standards that will serve as the basis for the “grid” and agrees on common implementation guides for the entire community.

Although the MHDC convenes these standards and policy committees, the other organizations in the state (NEHEN, MA-SHARE, and MaeHC) agree to implement, test, and enforce the use of these standards and policies. For example, MAeHC will fund the installation of an electronic health record in a clinician’s office only if it meets the interoperability requirements specified by the technical advisory board, enabling the secure exchange of clinical data across the continuum of patient care.

**Success Factors in Massachusetts**
Over the past decades during which the authors have worked with statewide organizations, many important success factors have emerged from community connectivity projects. While room exists for alternative approaches (Table 1), the authors believe that the factors outlined below significantly contributed to progress in Massachusetts:

**Openness and Transparency**
Community connectivity efforts must be open and transparent on several levels. All four of our community connectivity project organizations have open membership to all constituents: payers, providers, patients, vendors, and employers. All activities of our organizations are communicated openly via Web sites, newsletters, and meeting minutes. All our intellectual property including source code, policies, and legal agreements are shared openly across the community. We do not require proprietary software and we emphasize the adoption of broadly accepted industry standards. This openness results in our organizations being inclusive rather than exclusive. The climate of openness creates a trusted forum where organizations can set aside their competitive concerns.

**One Member, One Vote**
We recognize that the health community is composed of small community hospitals and large integrated delivery systems, small payers and larger payers, solo practitioners and multispecialty groups. The governance in all our community connectivity organizations follows a Senate model rather than a House of Representatives model. Each organization represented has one vote regardless of their size or economic power.

**Cost Avoidance Model**
In health care, there are many intermediary organizations such as clearinghouses, which charge on a “per transaction” basis for connectivity services. Because the cost structure of the infrastructure needed to provide such services has relatively high fixed costs and relatively low variable costs, we believe that collaboration to jointly invest in the fixed costs to reduce overall costs for all is a more effective model than a transaction fee or service chargeback model. While significant seed grants from outside organizations have contributed to the projects described (see authors’ acknowledgments), to date, all our community connectivity organizations’ ongoing projects are funded by community collaboration such as in kind contributions of effort and by yearly subscriptions to sustain the collaboration. In this fashion, we make commerce as frictionless as possible and keep our operating costs low. All participants benefit from the economies of scale achieved by sharing the up-front fixed cost and creating connectivity together as a region rather than working separately on disjointed and redundant solutions.

**Coordinated Decentralization Rather Than a Single Regional Database**
The ONCHIT request for information summary and the Connecting for Health Common Framework both describe decentralized, federated, and coordinated models for clinical data exchange. The definition of “decentralized” is that there will not be a single centralized database of the nation’s health records maintained at Health and Human Services in Washington, DC. The degree of decentralization implemented regionally will vary based on the preferences of each community. In Massachusetts, databases are centralized at the level of hospitals, payers, and integrated delivery networks but not at the level of the entire state or region. For example, CareGroup is a collaborative of four hospitals using separate clinical information systems, but “virtually” centralized by a single set of Web services for clinical data sharing with the RHIO. Our experience in Massachusetts is that local institutions understand local community policies and can serve as trusted stewards of data. Although we use a statewide, centralized, master patient index, we have not implemented a patient-identified centralized database of clinical data, minimizing the possibility that these data can be compromised by hackers or contain inaccurate information out of sync with that in hospitals and doctors’ offices. In addition, our experience with Community Health Information Networks in the 1980s taught us that local institutions are reluctant to release their clinical databases to a third-party organization to maintain. Our approach, which leaves the data inside the firewalls of participating institutions, but delivers them directly to the provider in response to a secure Web-based query, has been accepted throughout our communities by privacy advocates, patients, and clinicians. Since other RHIOs outside of Massachusetts, such as Indiana, have chosen to centralize data to a greater extent, our experience is a reflection of local community preferences.
RHIOs Perform Many Different Roles
Convening and operations require very different individual and organizational skill sets. It is possible to have a single organization do both, but it is not necessary. Having overlapping memberships in multiple organizations is key to building trust and getting consistency across organizations. It can be taxing on the individuals who are involved in multiple meetings, but is a key ingredient in formative stages and less important once the organizations have reached steady state. Once trust is built among individual leaders, much can be accomplished without big summit meetings.

Comparison to Other Statewide Efforts
Although Massachusetts has been an early innovator in clinical data exchange, other states have significant early experience in creating RHIOs and data-sharing organizations. California, Indiana, New York, and Tennessee have adopted their own strategies, governance models, and architectures, as summarized in Table 1. Similarities to Massachusetts include the creation of a regional master patient index, the use of a common implementation guide for data exchange, and the harmonization of security/privacy policy to support federated authentication. Differences include the degree of centralization of databases, funding models, and governance structure. For example, Indiana has chosen to use common data exchange standards to replicate data into a single central database that is then used to create a community-wide clinical summary.

Summary
The price of not moving forward with RHIOs is high. Health care in the United States is delivered in a heterogeneous and uncoordinated fashion, creating islands of patient information in providers’ offices, hospitals, and long-term care facilities. The end result can cause waste and error. In the state of Massachusetts alone, it is estimated that $4.5 billion per year is spent on inappropriate or unnecessary care, often the result of redundancy due to lack of patient information integration. The problem is national in scope. At the 2005 meeting of the National Governor’s Association, the governors of the states of Massachusetts, Indiana, Missouri, Michigan, and Tennessee discussed that Medicaid budgets are spiraling out of control and the only solution on the horizon is health care IT to coordinate appropriate care, reducing cost and improving quality.

Organizations in Massachusetts have evolved to provide the standards, policies, education, infrastructure, and implementation required to achieve the community connectivity that is fundamental to solving the myriad problems endemic in U.S. health care today. The MHDC convenes our committees and educates our stakeholders. NEHEN connects our payers and providers for administrative transactions. MA-SHARE provides the community utilities needed to implement clinical connectivity. The MAeHC ensures connectivity to our utilities by implementing standards-based technology in provider offices.

Working together, these organizations offer value to all stakeholders while at the same time building the trust necessary to incubate and test new ideas and create ever greater value over time. Over the next several years, we will continue to learn a great deal about regional health information exchange including the business models required to sustain community organizations. As these lessons are learned, we will communicate our experiences openly with the hope that our success can be shared and our failures avoided in other regions of the country.

References