Application of Information Technology

Health Care IT Collaboration in Massachusetts: The Experience of Creating Regional Connectivity

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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 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 Massachusetts eHealth Collaborative [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.

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 MDHC was founded as a nonprofit coalition by 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 a third-party organization that would normalize and redistribute the data for aggregate analysis. Outside Massachusetts, other states began similar activities in the mid-1980s. While all states collect data for public health purposes (birth and death certificates, communicable diseases, maternal and child health), only 37 states have mandates to collect health care systems data. The early work was important to Massachusetts for two reasons: it enforced the use of standards for...
data collection and it required the information systems
departments of the hospitals in the state to collaborate with
each other.

In 1995, Massachusetts data-sharing activities led to the crea-
tion 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 poten-
tially save millions of dollars on transaction costs and could
redirect these health care allocations toward patient care in-
stead 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 con-
nectivity, enabling appropriate sharing of interorganizational
health care data among the various participants in the health
care system, including patients, clinicians, hospitals, govern-
ment, and payers. Its operating goal is to serve as the clinical
“grid,” providing community utility services that support se-
cure clinical data exchange just as NEHEN provides adminis-
trative 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 to-
gether across different sites of care. Early in MA-SHARE in-
vestigations, 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 neces-
sitate 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 Connect-
ning 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 (Table 1), but all have imple-
mented the notion of a regional master patient index or RLS.
The MA-SHARE RLS will be a community-wide master pa-
tient 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 mini-
mized. 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: 5555555</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 indi-
cated in the following example:

| Institution: Regional Drug Treatment Center | Identifier: 11111111 |
| Institution: County HIV Clinic | Identifier: 22222222 |

By requiring consent, the RLS will ensure that the patient re-
 mains in control of the institutional entries that are main-
tained 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 con-
nect to one another and find and exchange records as needed
for patient care, that they can do so without requiring a uni-
fying patient identifier or a central store of clinical data, that
the system can allow participation even by relatively techni-
cally 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 will begin 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
Table 1  

<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>

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. 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 must be represented in a standard format, and thus developers should have community-wide implementation guides that mandate the use of well-accepted standards to build a clinical data exchange.
encountered during MedsInfo-ED was that state privacy laws prevented the sharing of mental health and human immuno-
deficiency virus prescription data.

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 that 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 multidisciplinary 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 MaHeHC) agree to implement, test, and enforce the use of these standards and policies. For example, MaHeHC 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 its 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 gifts 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 ONC HIT request for information summary 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.

Similariies 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, 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 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**


