Health information exchange: persistent challenges and new strategies

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ABSTRACT
Recent federal policies and actions support the adoption of health information exchange (HIE) in order to improve healthcare by addressing fragmented personal health information. However, concerted efforts at facilitating HIE have existed for over two decades in this country. The lessons of these experiences include a recurrence of barriers and challenges beyond those associated with technology. Without new strategies, the current support and methods of facilitating HIE may not address these barriers.

INTRODUCTION
Personal health information is not utilized to its full potential to support effective and efficient care due to fragmented information creation and storage. Health information systems are typically isolated, within hospitals, physician practices, laboratories, or pharmacies. Changes in insurance coverage, reliance on multiple providers, and increases in specialty care add more and more potentially relevant, but disparate, information into a fragmented, non-interoperable non-system.

Numerous factors in our society underscore the need for changes to this state of isolated, fragmented health information. We are a mobile population requiring access to vital information in different locations. For example, many retired Americans receive treatment in very different locations seasonally, and increasingly prevalent chronic conditions, like diabetes, can only be managed by information-based care management. Many obvious patient safety and quality issues arise in the handoff of patients among providers that fail to share necessary information. Natural disasters displace individuals to locales with unfamiliar providers and can destroy or render inaccessible existing health information repositories. The growing use of pharmaceuticals and associated recalls of drugs from the market may call for immediate identification of affected individuals. Finally, the likelihood of serious pandemics calls for rapid identification of ill persons and accurate immunization histories.

Policy makers, researchers, industry groups, and healthcare professionals identify health information exchange (HIE) as a solution to these problems. HIE is the process of sharing patient-level electronic health information between different organizations; the potential effects of making previously unavailable patient-level information available to healthcare professionals are widespread and address nearly all of the Institute of Medicine’s quality aims. While HIE promises cost and quality improvements, to date we lack substantial and consistent empirical demonstrations of the effectiveness of HIE.

Title XIII of the American Recovery & Reinvestment Act of 2009, also as known as the Health Information Technology for Economic & Clinical Health (HITECH) Act, is the most recent example of federal support for HIE. HITECH requires electronic health records (EHR) be ‘connected in a manner that provides...for the electronic exchange of health information to improve the quality of healthcare’ in order to be eligible for any incentive payments. This builds on the previous administration’s call for interoperable health information technology and its creation of the Office of the National Coordinator for Health Information Technology (ONC). While broad federal support for HIE is relatively new, efforts at HIE are not. For nearly two decades organizations and collaboratives have tried to facilitate HIE; unfortunately, the failures far outnumber the successes. The history, problems, and subsequent lessons of HIE efforts offer insights and options for increasing the probability of successful, meaningful HIE, today. Table 1 summarizes the key features of these efforts.

COMMUNITY HEALTH MANAGEMENT INFORMATION SYSTEMS
History
The Hartford Foundation initiated community health management information systems (CHMISs) through grants to seven states and cities in 1990. Fundamentally, CHMISs were a community and payer-centric means to healthcare assessment. A centralized data repository that contained individual level demographic, clinical, and eligibility information for a geographically defined community provided data to stakeholder organizations (eg, local agencies, payers, employers, and researchers) who were consumers of the data for assessment activities and other purposes. A secondary component of CHMISs was a transaction system to facilitate billing and patient eligibility information retrieval in order to reduce costs.

Problems
The primary problem CHMISs faced was a lack of affordable and effective technology. CHMISs occurred prior to the advent of cheap, reliable, high speed internet access; a CHMIS required costly network connections, hardware, and software in organizations where these types of technology had
not previously existed. Also, CHMIS efforts discovered the newfound challenge of integrating data sources that had never before been combined.17

Yet not all problems were technical. The very new idea of collecting personal health information into a single repository aroused security and privacy concerns from patients and control and ultimate usage concerns from providers.13 18 19 In Iowa, for example, physicians acted on these concerns and resisted the local CHMIS by successfully lobbying in the state legislature.11 Second, the geographically defined exchange required cooperation and consensus between competing providers, which in some instances was never achieved.19 Lastly, CHMISs were unable to transition from grant funding to self-sustaining revenue streams. The disappearance of grant dollars meant operational costs would have to be borne by the participants, making the value proposition less attractive.11 20

Lessons
The lessons from the CHMIS experience include the need for a clearly defined purpose and effective political support. Both are prerequisites to overcoming provider fears regarding the use of data, and the problems posed by competition. Assessments consist of those who are doing the measuring and those who are being measured. If the goals of an HIE effort include the assessment of the quality of care, then it is the concerns of those organizations and providers being scrutinized that become paramount. It seems nearly impossible to garner support for any effort at assessment without clearly explicated measures, foci, methods of reporting, and included entities. Likewise, organizational change supporting HIE requires sufficient political support, not simply weak legislation or overtures.21 HITECH provides strong incentives for the adoption of HIE supporting technology. However, instead of HIE-specific legislation, it may be the current interest in pay for performance, accountable care organizations, bundled payments, medical homes, hospital acquired conditions, or quality outcomes that enables political leaders to define a clear public purpose for exchanging data that can withstand objections regarding data ownership.

COMMUNITY HEALTH INFORMATION NETWORKS

History
In many ways community health information networks (CHINs) can be considered as the mirror opposite of the CHMIS experiment. CHINs developed in communities interested in the concept of HIE, but without community and payer stakeholders as the efforts’ primary leaders; CHINs were principally commercial endeavors.15 In contrast to quality assessment objectives, CHINs prioritized saving on the costs associated with moving data between providers,15 22 without ‘any commitment to make public community health level data.’19 Lastly, not wishing to relinquish data to a centralized repository, the prototypical CHIN employed a transaction-based approach that maintained the independence of each provider’s own database.15 Despite the fact that anywhere from 75 to 500 CHINs existed or were in the planning stages during the 1990s, most failed to survive.13 23

Problems
The focus on providers saving costs on information transmission caused two different, but problematic firsts. The role for the community-focused stakeholder was minimized to the point where only competitors were left at the table.13 Again, competitive relations posed problems as members limited the type and amount of information exchanged24 or limited themselves to a ‘read only’ basis in order to protect what was deemed as proprietary information.25 Second, the role for technology vendors was increased by the potential for fees associated with electronic transmission.26 Existing vendor commitments strained relationships between potentially partnering healthcare organizations, and vendors reportedly pitted the respective interests of hospitals and community physicians against each other.26 27

While CHINs required technological capacity building for exchange partners and networking connectivity investments, these were less technical challenges in nature than they were value proposition or return on investment (ROI) problems.28 29 What in hindsight appears to be both ominous and disconcerting, the introduction to a 1995 special issue of Healthcare Information Management stated, ‘It is nearly impossible to cost justify a CHIN.’30 Likewise, the Congress Office of Technology Assessment reported, ‘No one has demonstrated whether or not CHINs are cost-effective’.15 Given the capital costs to build infrastructure and expectations of resultant financial benefits, CHINs obviously needed to make money. However, not all CHIN participants contributed equal financial resources, which resulted in different definitions of acceptable ROI and levels of commitment among participants.25 31 While estimates suggested cost savings,32 33 and even the Wisconsin CHIN was reportedly reducing participant transaction costs,22 hospital executives questioned the potential for widespread ROI.34

Lessons
The value of HIE cannot be defined solely in terms of benefits accrued to providers or any other single group. In fact, the insufficient financial returns to vendors serving the ‘information transactions’ between providers shows that this aspect of HIE is not sufficient in and of itself to attract financial and political support. The value of HIE cannot be parcelled out in such a minute fashion, but must be considered in terms of...
benefits to all participants in the healthcare system: patients, providers, payers, and communities. In similar fashion, the cost of HIE may need to be borne by the larger community or market area, and not simply by the largest groups of payers and providers.

Additionally, HIE requires collaboration among competitors and the healthcare industry has difficulty with this prospect. While notable exceptions exist, reluctance to engage in widespread information sharing is nearly ubiquitous among providers, extending from small medical practices to large hospital systems. Other equally competitive industries have managed to survive and thrive with information exchange, but not healthcare.

REGIONAL HEALTH INFORMATION ORGANIZATIONS

History

A regional health information organization (RHIO) is a neutral, third-party organization that facilitates information exchange between providers within a geographical area to achieve more effective and efficient healthcare.35 Unlike previous efforts, RHIOs developed during a period of significant political support, as the ONC identified RHIOs as the ‘basic building blocks’ of the national health information infrastructure and interoperability was made a national goal.36 Additionally, RHIOs gained prominence in the years during and after the influential Institute of Medicine (IOM) Crossing the Quality Chasm reports, which raised the awareness about serious quality and safety shortcomings of our healthcare system.37

As many as 200 RHIOs exist nationwide, varying in the number of collaborating organizations, types of data exchanged, architectures, and progress towards actually sharing information.38 39 Architecturally, RHIOs employ either the CHMIS approach of a centralized database, the CHIN model of federated independent databases, or some combination of the two. The ONC promotes no single model. Since quality under the IOM definition includes the dimensions of effectiveness and efficiency, RHIOs can legitimately claim both general quality and cost savings as objectives.

Problems

The following observation echoes those of a decade ago: ‘…the main obstacle to increasing the number of HIEs and RHIOs is the lack of a sustainable business model’.40 Despite technological advances, RHIOs still need to: assure security, integrate disparate data sources, store data, administer databases, provide technical support, create and maintain a master patient index or record locator service, and find technologically capable exchange partners. RHIOs may require upwards of $12 000 000 for development and $2 000 000 to $5 000 000 in annual operating costs.41 42 Paradoxically, while local hospitals, due to size and resources, may be focused on as the primary financial contributors to a community’s RHIO, hospitals have been identified as the type of organizations that may have the most difficulty in showing a return on this investment.42

Also, the collaborative nature of HIE continues to raise barriers to RHIO participation and success. Health service organizations do not trust competitors with proprietary information, either to keep it secure or not to turn around an attempt to exploit it for a competitive advantage.43 44 Distrust and questions about control over information may not scuttle a RHIO, but it may limit what data are available, who is allowed to see the information, or for what populations data will be included in the exchange; any of these conditions may limit the effectiveness of the exchange currently and in the future. In addition, while privacy laws allow for the sharing of information between organizations for the purpose of patient care, RHIOs still have to ensure patient privacy.45 Lastly, fears of legal liability from unlawful disclosure of information can also damage the potential for exchange, as this risk has to be compared to any potential rewards.46

Lessons

Technological progress does not automatically fix the problems in healthcare information sharing. RHIOs established that the deleterious effects of competition are not dependent on the technological architecture. Competition between providers negatively affected CHMISs’ centralized data repositories and CHINs’ network approach to exchange; and the effects of competition still hamper RHIOs ‘pick your own strategy’ approach. Even adopting architectural strategies that ensure providers retain data control cannot overcome the reluctance to share ‘their’ data with competitors. Legitimizing RHIOs as a vehicle for HIE is a start, but it does not in and of itself foster collaboration between competitors.

The RHIO experience also demonstrated that grant funding is not a viable alternative to self-sustaining revenue streams. Despite technological advantages over their predecessors, RHIOs are still costly. Numerous federal, state, and private grants help overcome start-up and ongoing costs.49 However, continued dependence on external grant funding may point to poor sustainability potential,47 and evidence that an attractive value proposition for those participating organizations has not materialized.48

Lastly, long-term financial uncertainties pose enough risk to upend even the most technologically advanced effort. Complicating the ROI problem is the growing recognition that RHIOs face a long time horizon before what may be termed functionality, profitability, or sustainability are achieved. The combination of a long timeframe that may extend over many years with uncertain results is obviously not a favorable condition for success. Technically, this has always been a problem for those interested in HIE. During the launch of CHMISs and CHINs there were no really successful standards for comparison. However, RHIOs enter into a landscape that is much more diverse, with more than one effort that has managed to survive to maturity making this long timeframe more evident. While grant funding and HITECH incentives may help meet start-up costs, neither may ever produce a convincing value proposition for those likely to lose from more efficient and informed healthcare. The reality of the situation is that efficient, effective healthcare primarily benefits the patient, their community, but not necessarily providers. Short of additional clear incentives or regulation, ROI for providers is long to develop and difficult to identify.

STRATEGIES

The Obama administration reportedly envisions a future of lower cost and higher quality healthcare, and rapidly growing adoption of health information technology is to be a key lever in achieving such a future. HIE is forward as a vehicle for supporting these goals. Achieving these goals, however, requires strategies for overcoming obstacles encountered in past efforts. While there is the promise of additional support for the myriad computers, electronic records, and expanded connectivity, technology is not the only challenge to meaningful HIE. In light of these realities, what steps do we take from here?
Personal health records

One ostensibly appealing option is to abandon organizationally facilitated HIE efforts for an individual consumer-based model. Recently, the Markle Foundation suggested that providers who populate personal health records (PHRs) with electronic information be considered as meeting the objectives of HITECH. Intuitively, the PHR has appeal as it eliminates collaborative governance challenges, trades providers’ high cost technology for patient managed lower cost technology, and places information of educational value directly in the hands of patients. However, PHRs still require technologically capable and willing exchange partners. For example, physicians may be reluctant to accept information where maintenance, accuracy, and completeness is solely the responsibility of the patient. Furthermore, PHRs cannot completely ignore organizational behaviors. If the PHR application is hosted by a RHIO there is no reason to believe that the barriers that prevented complete provider participation and patient information sharing would immediately disappear. Even if the PHR is maintained by a third-party vendor like Google or Microsoft, it would not ensure that all of a patient’s providers would participate. Without the provision of complete information and the guarantee that PHR information will be accepted by other organizations and providers, PHRs will risk simply becoming another repository of incomplete isolated information.

Embracing a PHR model of HIE also comes at a cost to society and the overall healthcare system. While individuals may benefit from increased access and control to their personal health information, the PHR may lack a single data repository that could offer additional public health benefits. Without such a repository, HIE has less potential to detect disease outbreaks, identify public health threats, and efficiently report notifiable conditions. Additionally lost are opportunities for large, population-based research on healthcare intervention effectiveness. A PHR model thus removes additional public goods from an HIE value proposition.

Employ institutional incentives and regulation

HITECH’s ‘connected in a meaningful manner’ requirement has the latitude to allow for minimal HIE participation by providers unless more is specified. History suggests that providers will not necessarily maximize the amount of information exchanged or the number of information exchange partners of their own accord. The Centers for Medicare and Medicaid (CMS), as a federal institution, has the power to rapidly change provider behaviors through two different mechanisms. First, simply as the nation’s largest payer, CMS could make participation or membership in an RHIO a requirement for reimbursement. Second, HITECH requires meaningful use of EHR systems, but the legislation did not include any specific measures. CMS, working with the Office of the National Coordinator to create these measures, can set high and specific standards outlining both the type of information exchanged and the expected breadth of information exchanging partners. So far meaningful use only requires that the exchange capability be tested annually. The choice of clinical quality measures that can only be effectively calculated when exchange efforts are present could foster adoption HIE. An example would be measures dealing with patient care coordination.

Despite the obvious push for health information technology adoption, current events in the development of meaningful use definitions clearly signal that the true objective of the HITECH legislation is improved quality. In that regard HIE could be considered as a supplement or augmentation of any existing strategies to improve quality and reduce costs like global budget restriction, rate regulation, bundled payments, or even penalties for rapid readmissions. Ostensibly, the existence of information on the care a provider’s patients receive at other locations can support the effectiveness of these types of approaches. However, the primary adverse effects of effectively mandating HIE participation would be pushback resulting from the failure of government agencies, other payers, or professional organizational organizations to clearly present a business case for how the HIE can benefit the individual providers in doing their job and maintaining revenues in a time of significant change.

Treat HIE as a public good

A fourth approach is to consider the HIE as a public good, one which can benefit all individuals simultaneously; attempts to exclude any one individual are too costly to the larger public. Applying the first condition to HIE, individual patients, their communities, and all of society can simultaneously accumulate the benefits of effective HIE in terms of more effective health care, improved safety, and reduced costs. Applying the second condition, the costs of failing to include individuals within HIE efforts far exceed the benefits of such exclusion. In the case of all-hazards public preparedness, HIE-based discovery and monitoring of health and treatment within a disaster context is a very significant public good; exclusion of significant populations from HIE places the larger public at great risk in such instances. Moreover, those without effective coordination of care under normal circumstances are nonetheless at risk for adverse outcomes, and the unavailability of information at the point of care increases the probability of dangerous drug interactions, unnecessary or duplicative tests, and ignorance of other possible co-morbidities. Further support for this contention comes from the apparent probability of positive externalities for some health providers engaged in HIE. The marginal social benefit can reasonably be expected to be greater than the marginal private benefit for diagnostic laboratories or for hospitals that do not serve emergency cases or have little uncompensated care burden.

A clear public good focus is a direct solution to the paradox of geography inherited from a history of localized exchange. On the one hand, focusing on a local market means that physicians are more likely to know and therefore trust other providers as information sources, and also makes the probability of actually improving patient coordination and quality more reasonable. A small geographic exchange region, on the other hand, increases the probability that competition among organizations will inhibit the effort. Moving toward HIE as a public good—possibly structured as a public utility supported by government, and/or payers and providers—could simultaneously overcome these problems of competition, retain the benefits of localized exchange, gain the benefits of broader exchange, and address the issue of sustainability. Providers would know that they all are operating under the same rules of information sharing. HIEs, operating as ‘public utility infomediaries’, would bring existing and newly discovered transaction efficiencies and quality gains along with other valued forms of feedback to a range of markets or public entities.

Such a public utility based model covering a wider geographical region could, for example, incorporate rural settings and more distant urban locales that are home to specialists or referral facilities, and thereby add to quality gains. Such HIE transactions could be especially important in support of rural patients, physicians, and hospitals who need the clinical...
information associated with rural patients’ visits to urban specialists or hospitals. Such information can ensure effective management when such patients return to the care of their local provider.

**Rely on the effects of disruptive innovations**

Finally, HIE could well be the beneficiary of a number of disruptive innovations that are likely to significantly reshape American healthcare.\(^6^0\) One instance might find that continued high numbers of uninsured, developing health insurance arrangements, or changing consumer habits will prompt providers to adopt additional quality improvement efforts, which could include HIE. For example, an urgent care center that is connected to an RHIO or other HIE facilitator could have access to all the information on patients in the area and therefore might not need to repeat a test or x-ray, or pursue certain aspects of medical history irrelevant to the final diagnosis. Thus the service is cheaper and faster for patients than if he or she had gone to an ER or a new physician. In turn, traditional providers, faced with such disruptions from retailer-based medicine, urgent care facilities, employer clinics, or relatively inexpensive hospitals on the other side of the globe, may be willing to join government and employers to support HIE.

New approaches to managing chronic illness and associated changes in roles and responsibilities for non-physician healthcare professionals is another instance that might support HIE development. Because chronic disease is currently the most costly aspect of healthcare, a great deal of attention is placed on finding innovative approaches to managing such conditions. Many of these conditions are in the arena of precision medicine, where well-understood routines of care are available and can be supported by non-physicians. Diabetes nurse educators, licensed practical nurses, certified community health workers, patient navigators, and peer behavior health counselors within Assertive Community Treatment teams are just a few of the non-physician contributors to chronic disease care. Coordination of care is especially important to such chronically ill patients and the exchange of clinical information is critical to connecting the individuals who participate in their care.\(^6^0\) HIE is likely to be deemed increasingly valuable to providers who are more loosely linked, especially as they are enticed by incentives to support coordination or threatened with penalties for failures of care coordination, for example, preventable readmissions.

A third example that may increase HIE efforts or even create new forms of HIE flows out of the potential for natural or manmade hazards. HIE has tremendous potential to greatly increase abilities at the local, state, and national level to identify public health threats, detect disease outbreaks, efficiently report notifiable conditions, and evaluate and report effective treatment protocols. Providers of healthcare would be critical sources of information for such efforts and, in turn, would benefit from the information available from other sources. The constellation of threats and opportunities suggests that national and state agencies concerned primarily with national security, bioterrorism, or natural disasters may become significant advocates or funders of HIE. The challenge of widespread HIE adoption would then be solely related to information content as the interorganizational business architecture and information architecture would already be in place.

**CONSIDERATIONS**

This assessment suggests the following strategies for continued HIE development fitting the mixed economy of the US health service and public health system and supporting the multiple benefits of HIE to payers, providers, patients, and the larger public.

First, adopt an improved business model, and forego those that are primarily focused on incremental cost savings to providers. As the CHINs’ experience showed, attempting to define the benefits of HIE as incremental gains for each participant is the wrong approach. Move HIE facilitating organizations to a public utility model where a provider’s and insurer’s cost of doing business with the Medicare system or within a state includes the provision of patient level data for HIE. Cost savings then are more likely to accrue to the larger health system (payers and patients), with additional quality incentives encouraging and benefitting those providers who contribute to and use HIE.

Second, do not separate the public health benefits from the healthcare benefits, but meld private medicine transaction-based IT benefits and public good-based IT health benefits in supporting legislation, regulation, funding, and promotion. HIE potentially benefits providers, organizations, patients, and the public. This review illustrates that past efforts have attempted to satisfy the needs of only one or a couple of these groups at a time. Promotion and support of HIE must be broader to include all potential beneficiaries. This can be accomplished only if legislation, regulation, and funding support widespread HIE. The anticipated benefits of more data to inform physician decision making, sparing patients of needless tests, helping organization identify inappropriately managed patients, and improving the health of the public will only be achieved by HIE that does not exclude providers in an area, limit what data elements are available, or restrict exchange to specific subpopulations. To date, this type of widespread HIE has been elusive.

Third, ensure that HIE relies on the best and safest technology for information exchange; carefully monitor and assess implications that new technology and entirely privately driven solutions might have for quality care and public health security. HITECH already provides for the oversight and certification of EHR systems, and the Certification Commission for Health Information Technology already has an HIE working group. Monitoring responsibilities could fall to an entity like the HHS Office of the Inspector General, which already can impose penalties for health information confidentiality violations. Without some degree of regulation, sharing of health information (either patient related data or provider assessments) via HIE can put both patients and providers at risk.

Fourth, with federal government cooperation and support, encourage states to be the fundamental geographical unit for HIE activities. Public health is the states’ purview. That fact, in conjunction with states’ health insurance regulation and Medicaid authority, means that each state has sufficient authority and interest to create statewide HIE. The federal government can cooperate as a partner in Medicaid, through Medicare and ERISA, and as leader in public health informatics and response. Such an arrangement places the state’s authority behind efforts to share patient information among providers in order to provide for ongoing improvements in the health of their residents. Furthermore, federal support may be necessary given the high costs of HIE and the current fiscal constraints of balanced budgets in the states.

The past 20 years have witnessed fits and starts in addressing the nation’s need for HIE. We are in the very early days of the widespread adoption of the technologies necessary to adopt effective HIE. However, a more careful examination of history indicates that in those organizations with the necessary
technologies already in place, with rare exceptions, HIE did not come about automatically or without challenges. Why can we no longer afford to wait? New technologies are quickly overcoming ‘technological barriers’ and ‘technology-based objections’ to data sharing. In fact, healthcare is well behind the curve on information sharing in comparison to many other industries. If we believe broadly accessible information is a path to significant improvements in quality, failure to act in a concerted fashion is likely to have a deleterious impact on health and healthcare nationally as cost constraints and provider shortages mount.

As noted, higher costs associated with a growing elderly population and chronically ill populations will strain the existing system. Today, HIE efforts cannot effectively target and support treatment in the face of pandemics or other disasters. Similarly, the potential of HIE to support scientific, evidence-based, approaches to healthcare remains largely unrealized even as information technology can provide patients with instantaneous, approaches to healthcare remains largely unrealized even as information technology can provide patients with instantaneous information from anywhere and anyone. Finally, failure to act on HIE to support improved healthcare efficiency and effectiveness can almost guarantee decline in economic competitiveness and competitiveness for quality healthcare.

As we move toward a new age in health information sharing, have we learned the lessons of the past? Electronic exchange, involvement of different organizations, and a geographical defined community are persistent features of our nation’s efforts at facilitating HIE. ‘(The details have changed over the years, the three basic components of CHMIS have endured and continue to this day…’11) To this observation we simply add that basic problems faced by HIE efforts have endured as well. Unless we address these problems via broad strategies tailored to the mixed economy and robust federal system of this nation, we are likely to see history repeat itself yet again.

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