

The State Of Regional Health Information Organizations: Current Activities And Financing

It is not yet known whether the current U.S. market-oriented approach—offering small grants and waiting to see which RHIOs flourish—will work.

by Julia Adler-Milstein, Andrew P. McAfee, David W. Bates, and Ashish K. Jha

ABSTRACT: Electronic clinical data exchange promises substantial financial and societal benefits, but it is unclear whether and when it will become widespread. In early 2007 we surveyed 145 regional health information organizations (RHIOs), the U.S. entities working to establish data exchange. Nearly one in four was likely defunct. Only twenty efforts were of at least modest size and exchanging clinical data. Most early successes involved the exchange of test results. To support themselves, thirteen RHIOs received regular fees from participating organizations, and eight were heavily dependent on grants. Our findings raise concerns about the ability of the current approach to achieve widespread electronic clinical data exchange. [*Health Affairs* 27, no. 1 (2008): w60–w69 (published online 11 December 2007; 10.1377/hlthaff.27.1.w60)]

THE RISING COSTS OF HEALTH CARE coupled with inconsistent provision of high-quality care have become major concerns for purchasers, providers, and policymakers. Health information technology (IT) holds great promise to help address rising costs by delivering greater efficiencies while simultaneously improving safety and quality. One particular use of health IT has received much attention: electronic health information exchange across provider organizations.¹ Some have advocated building a national health information infrastructure that will allow all health care providers to exchange data with each other.² However, most current activities have focused on local efforts through entities known as regional health information organizations (RHIOs). RHIOs are thought to have a

Julia Adler-Milstein (jadltermilstein@hbs.edu) is a doctoral candidate in health policy at Harvard University in Cambridge, Massachusetts. Andrew McAfee is an associate professor, technology and operations management, at Harvard Business School in Boston. David Bates is division chief, general medicine, at Brigham and Women's Hospital in Boston. Ashish Jha is an assistant professor at the Harvard School of Public Health in Boston.

greater likelihood of success than other strategies, given that they are locally based, and they may be linked together in the future to enable national exchange. Efforts to reap the benefits of clinical data exchange are widely embraced and remarkably nonpartisan.³

The appeal of electronic health information exchange (HIE) in general, and RHIOs in particular, is evident. An electronic, interconnected regional infrastructure represents the rational approach to handling the volume and specificity of health-related information required to efficiently deliver optimal care, particularly in information-intensive specialties such as internal medicine.⁴ As more provider organizations store data electronically, the natural next step is to electronically exchange the data with other providers. In part because of the complexity of having individual provider organizations (such as hospitals or doctors' offices) set up protocols for electronic exchange with each of the multitude of other provider organizations in a community, RHIOs have emerged to act as independent third parties, bringing stakeholders together and supporting HIE networks.

Despite enthusiasm for RHIOs as the agents that may bring about HIE, there are few empirical data on their activities or their sustainability. Many grant-funded RHIOs are proceeding under the assumption that HIE will create financial value via efficiency gains that can be captured to fund ongoing exchange. However, key financial beneficiaries (payers and purchasers) are not always involved, and many practical issues act as barriers. Although interoperability seems to hold great societal benefit, it still might not be possible to implement it sustainably under the current approach. In particular, if RHIOs are to succeed as small businesses, they must be built around sustainable business models, which requires both profitability and value creation for participants.⁵ From the policy perspective, it is essential to determine whether or not the current approach is succeeding.

Therefore, we undertook a study to determine how many RHIOs exist in the United States today, how many are facilitating clinical data exchange, what types of data they are exchanging, and what their sources of revenue are. This snapshot captures the progress of RHIOs to date and identifies potentially successful efforts that could serve as models for the next generation of RHIOs.

Study Data And Methods

■ **Overview.** RHIOs have been defined by the federal government as organizations that support state or other regional projects to help harmonize the privacy and business rules for electronic HIE.⁶ Within any particular setting, the structure of RHIOs varies based on the local health care delivery market and the stakeholders involved. With no widely accepted single definition of a RHIO, we defined it as any effort for which the primary purpose is to facilitate electronic exchange of clinical data between independent entities. Although there is much overlap with the federal government's definition, we sought to understand the current state of clinical data

exchange and therefore excluded efforts limited to administrative data exchange and those whose primary purpose is not facilitating data exchange.

■ **Identification of RHIOs.** To identify a comprehensive set of RHIOs, we began with the eHealth Initiative's (eHI's) compilation of state, regional, and local HIE efforts.⁷ The eHI is widely recognized as the most influential nonprofit organization working to further the adoption of health IT along with HIE. In July 2006 we identified 130 entities that had participated in the eHI 2006 Survey of State, Regional, and Community-Based Health Information Exchange Initiatives and had self-identified as being involved in HIE. We then asked national health IT experts if they were aware of other RHIO efforts not captured by the eHI. This identified another fifteen organizations, for a total of 145 potential RHIOs.

■ **Survey development.** We began by conducting in-depth, semistructured interviews with leaders from several well-known HIE initiatives to learn more about the functioning of RHIOs. Based on the interviews, we identified three stages of development that most RHIOs typically pass through (although not always in this order): convening stakeholders to pursue clinical data exchange, creating the infrastructure to support clinical data exchange, and, finally, exchanging clinical data across independent entities. We also identified the types of clinical data that might be exchanged (such as test results) and different funding sources that RHIOs might use to support their efforts.

We developed a survey based on these findings and incorporated suggestions from experts who reviewed the survey instrument. We then tested the instrument with a subset of RHIOs to ensure that the questions clearly conveyed our areas of interest and that the survey could be answered in fifteen minutes or less.

■ **Survey administration.** We sent an electronic survey to the contact person listed in the eHI directory or the director of the effort at all 145 RHIOs identified. For those who did not respond, we sent a total of three follow-up e-mail messages, and then, among those that still had not responded, we made multiple phone calls to request that they complete the survey. Based on this approach, we categorized the RHIOs into four groups: respondents to the survey, nonrespondents (if they declined to participate in the survey or were known to exist and did not respond to the survey), non-RHIOs (if they reported that they had never pursued clinical data exchange), or defunct. For a RHIO to be considered defunct, it had to meet all of the following criteria: (1) It could not be contacted despite e-mail messages, phone calls, and attempts to find updated contact information from several sources; (2) neither a Web site nor accurate contact information could be located for the organization when searched for using Google; (3) it was not known to exist by any of the health IT experts we contacted; and (4) it had been removed from the eHI directory as of 1 March 2007.

■ **Survey content.** In the survey, all respondents were asked to report whether they (1) had convened a group of stakeholders to discuss pursuing electronic clinical data exchange, (2) currently support such exchange or, if not, planned to at a future

date, and (3) supported such exchange between independent entities as of 1 January 2007.⁸ *Independent entities* were defined as institutions with no financial relationship or shared, central governance. RHIOs that only supported administrative data exchange were excluded. With many competing definitions of what constitutes a RHIO, many of the surveyed organizations do not consider themselves to be a RHIO. However, for the purpose of this study, we classified them as such if they met our inclusion criteria.

To help us understand the types of entities involved in data exchange, respondents who were supporting exchange between independent entities were asked to report the categories of entities providing data for exchange, the categories of entities receiving or viewing the data, and the categories of clinical data exchanged. They also reported the number of patients for whom clinical data exchange was currently possible, specific patient population(s) targeted for participation, and the data exchange functionalities supported. In our initial semistructured interviews, we encountered substantial resistance to reporting profitability metrics. Therefore, we chose to focus on revenue sources to assess financial viability. We asked respondents to report the sources of funding during each of the three phases of RHIO development: (1) before a technical infrastructure existed, (2) as the technical infrastructure was being built, and (3) once the technical infrastructure was in place and electronic data exchange was initiated. Funding sources were distinguished by participating entities (those providing or receiving data) and nonparticipating entities. Specific forms of funding were listed, and respondents indicated whether support from each source was substantial, moderate, or minor/none.

■ **Analysis.** The responses were reviewed for errors and omissions and then were combined to produce summarized results. RHIOs in which data were exchanged for at least 5,000 potential patients (“large”) were analyzed separately from those covering fewer than 5,000 patients (“small”). Given that a typical primary care physician might care for 1,500–2,500 patients, RHIOs that were designated as “small” usually involved very few providers or a small subset of patients. We focused our analyses on RHIOs that had achieved at least the minimal scale of 5,000 patients for whom data exchange was possible, which could serve as models for future expansion.

Study Results

Of the 145 organizations identified, seven reported that they had never pursued clinical data exchange and were not therefore RHIOs. Of the remaining 138 organizations, 36 organizations (26 percent) met all of the criteria for being classified as defunct, leaving 102 organizations that were possibly pursuing clinical data exchange. Of these, we received responses back from eighty-three, for an overall response rate of 60 percent (including defunct organizations) and an effective response rate among nondefunct RHIOs of 81 percent.

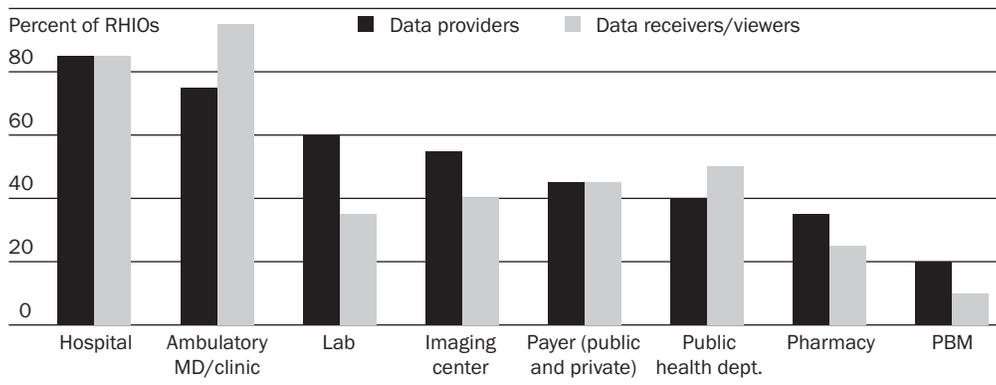
Of the eighty-three respondents, thirty-two RHIOs (38 percent) reported facil-

ilitating clinical data exchange across independent entities as of 1 January 2007. Three (4 percent) were facilitating data exchange between nonindependent entities (that is, physicians and hospitals that were part of the same integrated delivery network). Forty-five RHIOs (54 percent) were still in the planning stages, and three (4 percent) were temporarily stalled because of lack of funding but had not permanently stopped pursuing HIE in their communities. Of the thirty-two RHIOs facilitating clinical data exchange, twelve were designated as “small” efforts. They were typically narrowly focused efforts (for example, for Medicaid pediatric asthma patients) in small geographic regions. In the remainder of this paper, we present results for the twenty RHIOs that had achieved at least a modest size and whose experience might be instructive for future efforts.

■ **RHIO participants, activities, and focus.** Of the twenty modest-size or larger RHIOs exchanging clinical data, five had a specific target population for the data exchange, such as Medicaid enrollees, uninsured populations, and chronically ill patients (such as diabetics). Therefore, only fifteen RHIOs were focused on clinical data exchange across a range of patient populations.

Data on RHIO participants revealed that hospitals and ambulatory care practices provided data for exchange most frequently and also viewed data most frequently. In all but three of the RHIOs (85 percent), hospitals provided some of the data for exchange; in the same percentage of RHIOs, hospitals viewed the clinical data being exchanged (Exhibit 1). Ambulatory care clinics viewed data more frequently than they provided it. In all but five RHIOs, they provided some of the data for exchange; in all but one, they viewed the clinical data being exchanged. Laboratories and imaging centers were also common providers of clinical data for exchange but were viewers of the data less often. Public health departments and payers were involved in both providing data and viewing data in nearly half of the

EXHIBIT 1
Types Of Entities Providing And Receiving/Viewing Data In U.S. Regional Health Information Organizations (RHIOs)



SOURCE: Authors' analysis.
NOTES: N = 20. PBM is pharmacy benefit manager.

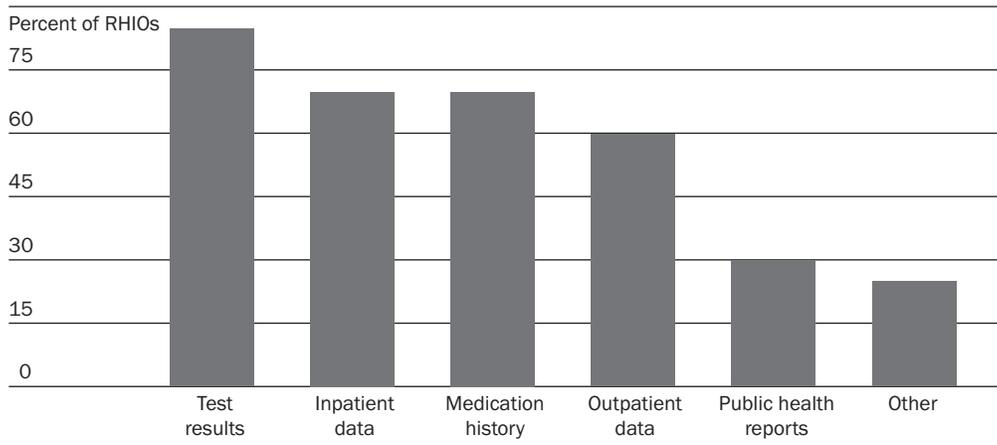
RHIOs we examined. Pharmacies and pharmacy benefit management organizations (PBMs) were infrequently involved (Exhibit 1).

When we examined the types of data being exchanged, test results and medication histories were the most common. Seventeen RHIOs (85 percent) exchanged test results (for example, laboratory, radiology), followed by fourteen RHIOs that exchanged inpatient data and medication history (Exhibit 2). Outpatient care data were exchanged in twelve RHIOs; a smaller fraction were involved in exchanging other types of data, such as public health reports. Eleven RHIOs exchanged at least four types of data, and only three RHIOs exchanged a single type of data (not shown).

The functionalities facilitated by RHIOs were consistent with the types of data exchanged. For example, viewing or delivery of results was the most common functionality, with 90 percent of RHIOs offering it. Clinical documentation (notes) and consultation/referrals were offered by half of the RHIOs. Five of them approached data exchange by offering electronic medical record (EMR) licenses in which the RHIO acts as a “middleman” between EMR vendors and participating care delivery organizations. In this approach, the EMR systems offered by the RHIO were set up to exchange data with all other participating entities, achieving systemwide interoperability. Only three RHIOs offered a single data exchange functionality (for example, delivery of results), while nine RHIOs offered five to nine functionalities (data not shown).

■ **RHIO funding sources.** Given concerns about the financial sustainability of RHIOs, we asked each organization about its funding sources. As RHIOs convened stakeholders and planned for clinical data exchange, time or in-kind resources were

EXHIBIT 2
Types Of Clinical Data Exchange Taking Place In U.S. Regional Health Information Organizations (RHIOs)



SOURCE: Authors' analysis.

NOTE: N = 20.

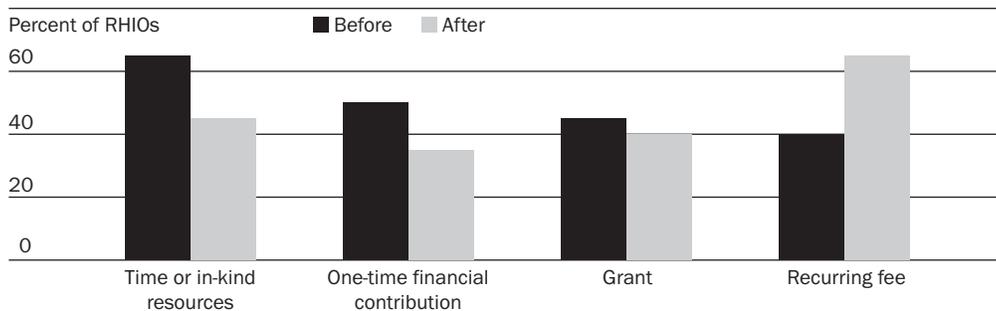
the most common source of support, with thirteen of the twenty RHIOs reporting that as a moderate or substantial funding source (Exhibit 3). One-time financial contributions and grants or contracts were less common but still important sources of support for about half of the RHIOs. Once the data exchange was up and running, thirteen RHIOs reported receiving recurring subscription or transaction-based fees as moderate or substantial sources of support. Other important forms of support in this phase of RHIO activity included time or in-kind resources (nine RHIOs), grants (eight RHIOs), and one-time financial contributions (seven RHIOs). Nine of the twenty RHIOs examined (45 percent) never received grant funding in any of their phases of development, and only 20 percent received grant funding during all stages of development. Six RHIOs received both substantial grant funding and other forms of financial support once they were exchanging data.

Discussion

When we surveyed RHIOs known to exist in July 2006, we found that nearly one in four of them were defunct by early 2007. Among the RHIOs that responded to the survey, about half were in the planning stages, and four in ten were exchanging clinical data. Moreover, of the 138 organizations initially identified as having launched efforts, only twenty were functioning at even a modest scale, and only fifteen were doing so for a broad set of patients. Of the subset of twenty RHIOs, thirteen were receiving user fees. Although we did not collect data on profitability, our results suggest that at most twelve of these RHIOs are self-sustaining, since eight continue to receive moderate or substantial grant funding.

RHIOs have received tremendous interest from policymakers. The Agency for Healthcare Research and Quality (AHRQ) and other federal agencies have provided substantial support to many of these efforts with the hope that as they get up and running, they will become self-sustaining. Our data offer both some hope and some reason for concern. Some organizations do seem to have sustainable

EXHIBIT 3
Forms Of Support For U.S. Regional Health Information Organizations (RHIOs) Before And After Initiation Of Clinical Data Exchange



SOURCE: Authors' analysis.
NOTE: N = 20.

sources of revenue; however, many others are failing early. Of those exchanging data, 40 percent were still heavily dependent on grants. Others have also found that few RHIOs are self-sustaining, with only 5 percent of RHIO efforts earning sufficient revenue to be profitable.⁹ Our results, in this context, suggest that young RHIOs face substantial challenges, and it is not clear whether even more mature RHIOs have a clear path to becoming financially sustainable.

Whether grant support is helping organizations that would otherwise fail, but will eventually become self-sustaining, is largely unknown. A few RHIOs we surveyed have never relied on grant funding, which suggests that in some communities, success without grant support is possible. The RHIOs that are functioning without substantial grant funding achieved success through the difficult work of building community support, developing key stakeholders' interest in clinical data exchange, and demonstrating the benefits. The advantage of grants is the ability to pursue implementation without establishing a self-sustaining revenue model up front. The disadvantage, of course, is that although it allows RHIOs to create infrastructure quickly, it might allow them to bypass the challenge of creating buy-in from stakeholders. The effort might be driven by the availability of funds as much as by a perceived community need for clinical data exchange, cultural readiness to engage in exchange, or providers' wish to share their data.

The Santa Barbara County Clinical Data Exchange, once heralded as the model for RHIOs, is a visible example of the risk in this approach.¹⁰ It recently shut down despite receiving substantial grant funding, partly as a result of its failure to obtain sufficient participation from local stakeholders. Although grant funding itself is not problematic (it provides RHIOs with greater flexibility to be innovative), some organizations may become dependent on this source of funding and fail to convince local stakeholders to share data and support the ongoing effort.

Whether RHIOs represent small businesses that need viable business models, which requires the ability to generate profits as well as value for participants, or public goods that require public financing is an important unresolved issue. The United Kingdom and other countries approach clinical data exchange as a public good that should be fully funded by the government. Our evaluation of the U.S. approach, which relies more on the small business model, suggests that these organizations' survival is tenuous at best and that surviving entities have structured their activities around exchanging results of diagnostic tests.

Given the sizable transaction costs typically incurred when laboratory and radiology results are printed and mailed, the value of electronic exchange to diagnostic centers and to providers is clear. Converting to an electronic process saves materials and staff time for labs and imaging centers, reducing their costs.¹¹ Automating the reporting of results also has benefits for providers. A study from Brigham and Women's Hospital found that a full-time primary care physician on average reviews 930 pieces of chemistry/hematology data and 60 pathology or radiology reports in a typical week.¹² Clinical results are often unavailable at the

time of the clinical encounter, with 81 percent of cases missing pertinent patient data in one study.¹³ Electronic clinical data exchange should increase the likelihood that results will be available in a timely manner, which will not only reduce costs but almost certainly improve clinical care.

There are several important implications of mature RHIOs' focus on viewing and delivery of test results. First, as reflected in our findings, provider organizations (hospitals and ambulatory care providers), labs, and imaging centers were the primary participants. Payers—a stakeholder likely to financially benefit from HIE—were noticeably absent, as were others with valuable clinical data (such as pharmacies).¹⁴ Second, test results are a small subset of the range of clinical data exchange that has been envisioned by policymakers. Although viewing and delivery of results may be a stepping-stone to broader exchange, it is also possible that efforts will stall at the current stage without a clear business model for comprehensive data exchange. A few RHIOs are pursuing models built on chronic disease management, EMR licensing, and performance reporting. Each has the potential to include a broad range of clinical data but may currently lack the market conditions that would create a compelling business model. Finally, the technical approach to viewing and delivery of results has led to little “end-to-end integration” with results available for providers on a secure Web site or via clinical messaging (that is, system to eyeball). This approach still offers substantial benefits for the end user but is much less expensive, technically easier, and far from the vision of full system integration.

This study has important limitations. The designation that RHIOs were defunct could have been inaccurate in some instances. If these organizations were still active, our response rate would have been much lower (60 percent as opposed to 81 percent). We think that this is unlikely, given that any RHIO that met all four of our criteria was almost surely not actively functioning. Second, it is early in the development of RHIOs, and we could simply be making an assessment that is “ahead of the curve.” In our evaluation of RHIOs' financial models, we only examined sources of funding and did not pursue whether the individual organizations were profitable or losing money because of the sensitivity of this question. In our initial interviews, RHIO leaders reported that few efforts were self-sustaining. Thus, we chose to focus on sources of funding, which is likely a more important indicator of sustainability, given that organizations can be profitable even when wholly dependent on grants. Finally, we were limited in our ability to collect more-detailed data about the numbers of organizations involved in each RHIO and the types of data each organization was providing. This limits the depth in which we can describe the activities that are occurring within these RHIOs.

In examining the activities and funding of RHIOs in the United States, we found a few early successes and many reasons for concern. The early successes were primarily involved in exchanging results of diagnostic tests between doctors, labs, imaging centers, and hospitals. Half of these organizations appeared to be po-

tentially financially viable and were generating revenue through payments received from participants. These early success stories are instructive, but whether they will serve as models for the next generation of RHIOs is not clear. We also found a substantial number of early failures, stalled efforts, and RHIOs that were heavily dependent on grants. Thus, the jury is still out on whether the current market-oriented approach of offering small grants and waiting to see which RHIOs flourish will work. Furthermore, whether these RHIOs and the next generation in the planning phases will be able to fulfill the vision of electronic HIE across U.S. communities remains to be seen.

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NOTES

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